Support for Australia's thalidomide survivors Submission 18

To the members of the Thalidomide Senate Inquiry,

I'm not sure what to write or how to say it but I will give you a look at my life.

Under the advice of her doctor my mother took thalidomide and later gave birth to me, on April Fools Day 1962. I was her third child with two older sisters. I had undeveloped arms, only two fingers on each and an extra toe. There are other underlying conditions that weren't obvious at the time. (heart problems, enlargement of part of my oesophagus, no gall bladder) You could say I was lucky that my mum took me home but it wasn't going to be a happy childhood. I know there are many factors in an unhappy marriage but I can't help thinking a disabled child may have been the breaking point. My dad used to beat up my mum and after divorcing drank himself to death (cirrhosis of the liver). My mum ended up abandoning me and my sisters to start a new family. During this ordeal I had surgeries to amputate an extra toe and move my big toe on my left foot so I could finally wear shoes. I am not sure of the extent of the surgery but I do have a six inch scar on my upper shin and my leg was in a cast for quite a while. I had to wear a helmet as a young child as I had terrible balance and often fell hitting my head (It's covered in scars). I also spent time at Montrose Home (it wasn't a home it was an institution), There they were supposed to teach skills to help me in life but mostly their ideas didn't work. The only thing I enjoyed there was going horse riding every Saturday, (a passion I still have today and perhaps the only time I feel somewhat normal around people is when I am riding but it comes with a lot of pain now). I was then raised by my elderly grandparents who were pensioners at the time. The main thing I remember as a child is always being different and often being bullied because of it.

When I was twenty I was hospitalised for diverticulitis (I had been suffering pains for years, the condition is rare in people under fifty and I don't know if thalidomide played a part in its cause). I almost died from complications when some stitching came undone and caused more of my Bowel to die. Eventually the surgeon had to

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decide whether to give me a colostomy bag or see if I could get by on a drastically reduced bowel. He decided to see if I could get by and I have but I never have solid stools and may need to make an emergency dash to the toilet at any time. This makes leaving my home very difficult when you have to use public toilets and you have arms like a T-Rex. Without the hooks I have screwed to the walls of my home toilet I have sometimes been reduced to dragging my bottom across the floor of a public toilet to get my pants down when help hasn't been available. As you can imagine this is a very unpleasant experience. As a consequence I don't eat on the days I do go out until after I return home and starve myself all day if I intend to go out at night.

Please understand that as a young woman I didn't have a high selfesteem. I finished school at year ten and I got married at twenty to a man who was manipulative and isolated me from the few friends and the little family I had left. When I was twenty five I gave birth to my daughter. The marriage broke down after twelve years and I then raised my daughter on the single parent pension, because for some reason they wouldn't let me have the disability pension. (Quite often I have found my disability does not fit under the accepted government criteria and they would have problems classifying me). I seemed to find myself in a few more toxic / abusive relationships over the next few years until I met husband number two and father of my other two children. We couldn't afford a wedding and got married at the court house. We have been together now for twenty years. During these years I have become more the person I want to be. I have reconnected with family and made friends or reconnected with old ones. But financially it has been hard. We have been raising our family on the pension. Having more children put more strain on my body and my husband gave up work to care for me and raise the children. Up till the time we started receiving our Diageo payments we were constantly going backwards financially not being able to afford anything apart from basic needs, we don't drink or smoke. We paid the bills but never had money to save. The payments from Diageo

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have helped but we were so far into poverty that we are only catching up on things like house maintenance and upgrading our car and dentistry (I use my teeth a lot and cannot rely on public health). We are hoping to replace our bathroom and laundry in the next few years to be more user friendly for me. The house we live in is small, really a two bedroom that had part of the lounge room annexed to create a third bedroom. It would be a dream of mine to be able to extend our home or move to a larger one. I worry about how we will survive when we have to depend solely on the pension when Diageo payments stop. My husband has almost no superannuation (only eighteen thousand) and the admin fees often exceed the gains.

Every day of my life I have been and am in pain. The human body is not designed to be used the way I use mine. My back is ruined, I have pains in my abdominal area, my heart has a dicky valve and will often thump to a crazy irregular beat. I don't know what the future holds but I do know it won't be pleasant. I am rapidly approaching the point in my life where I won't be able to venture out and I will be house bound. I would love my house to be a place of comfort, to be able to have air conditioning and a spare room so I can leave things on the floor where I can easily access them. I would love to have a home that is a refuge not one that will become a prison. I would love to have private health/dentistry and not be at the mercy of the public health system as I feel that when things get bad for me health wise it won't be just one thing, it will be a whole bunch of things go bad in rapid succession.

I would like my pension to be free of the assets test like blind people are. Other nations stood up and helped their survivors and I have always felt like the Australian government doesn't want to acknowledge us, just didn't care. I have lived my life in poverty thanks to Thalidomide. I feel the government has a duty of care to us survivors, you failed to keep this drug away from our mothers, you failed to help after we were born. Please, it's not too late to help us by giving us better financial assistance and health care.

Sincerely