

My name is [REDACTED] and I am a sister of a thalidomide survivor – [REDACTED]

Below are my comments relating to the Senate Inquiry into Support for Australia's Thalidomide Survivors.

(a) adequacy of compensation and support;

I believe that all financial compensation received by [REDACTED] to date has been hard fought for by groups such as Thalidomide Australia Inc. and Thalidomide Group Australia. While, this has been welcomed it will be inadequate to cover future costs of medical and home care.

While there have been large compensation payouts e.g. the Lynette Rowe case and the subsequent class action, [REDACTED] was not part of the class action.

Other forms of support have also been inadequate. Growing up in the 1960s and 1970s, there were no disability support staff in schools, [REDACTED] had to cope as best she could and develop innovative ways of dealing with everyday tasks. Also, such things as disabled parking and accessible buildings were also rare.

(b) responsibility for providing support;

My sister has always been fiercely independent but even with her resilience and courage there will always be physical limitations on what she can do. Simple everyday tasks such as personal hygiene e.g. toileting and grooming, dressing and preparing food become complex tasks requiring adaptations. [REDACTED] has learned to use her legs and mouth to compensate for the loss of her arms/hands e.g. turning off light switches with her feet, holding cups with her feet, using her mouth to retrieve money from her wallet or support her pen when writing, standing on chairs to hang clothes out (this might sound simple but try balancing without arms).

To date, [REDACTED] has been able to support herself:

- she had a job as a public servant until she had to resign due to health reasons
- has been able to perform most household tasks with adaptations
- she has until recently been able to drive a car with feet adaptations

However, with age the effects of thalidomide are magnified. [REDACTED] lives daily with severe back, knee and neck pain, arthritis, and increasing fatigue, all attributable to thalidomide. As a result, she is now requiring more support from family and paid care providers.

Throughout [REDACTED] life, our mother has provided support, helping with all physical tasks and providing emotional support. My mother has lived with guilt and regret everyday of her life since [REDACTED] birth, even though rationally she had no reason to suspect that a supposedly safe morning sickness tablet could cause such harm to her unborn child. Her ability to cope and provide [REDACTED] with much needed support still inspires me. It was Mum who comforted [REDACTED] when she was bullied by other children or was hurt by comments made by insensitive adults, and mum who instilled in [REDACTED] her can do attitude. All this has taken its toll on Mum who has also had to cope with depression.

Other family members have stepped up to help with the daily chores that [REDACTED] can no longer perform e.g. changing bed clothes.

[REDACTED] can no longer drive due to the deteriorating condition of her knees and now relies on family, friends and mobility cabs for transport. Using public buses is not an option as without arms to provide balance she has previously fallen and broken her nose while using a bus.

(c) provision of financial compensation;

Over the last 4 years, Thalidomide Group Australia has been seeking financial compensation from the Australia government. I believe the amount of compensation being sought is not excessive and will greatly improve the lives of Thalidomide survivors

(d) the role of the Australian Government in compensation and support;

British, Canadian and German governments have provided compensation packages in recognition of the on-going and increasing needs of thalidomide survivors. To date, the Australia government has not provided any significant support to Thalidomide survivors. I believe the amount of financial support being sought by thalidomide survivors is minimal in comparison to the amount of suffering they have endured and still endure on a daily basis. The money will enable them to adapt their homes to better suit their individual needs, pay for care providers and required medical treatments.

I appreciate that procedures change over time, but the fact remains that the Australian Government of the day was responsible for allowing this drug to be available in Australia to women like our mother. As all legal avenues for compensation against the manufacturers have now been exhausted I feel it now quite reasonably falls to the Australian Government to provide comprehensive ongoing support to the Thalidomide survivors in Australia.

Thankyou for allowing me the opportunity to address the issues my family has and continues to face as a result of the use of Thalidomide.