

The experience of UK thalidomide-damaged people (Thalidomiders) and the British government's financial support

A submission by the UK Thalidomiders Campaign Team to the Australian Senate Community Affairs References Committee, October 2018

Background

On 21 August 2018, the Australian Senate conducted a review of support for Australia's Thalidomiders requesting evidence and comment from the UK Thalidomiders Campaign Team, on:

1. How Thalidomide affected and continues to affect those it touched
2. How government support makes a difference to the lives of Thalidomiders

History of thalidomide

Thalidomide was created, manufactured, and marketed as a 'completely safe wonder drug' by the German pharmaceutical company, Chemie Grünenthal. It is likely they created it around 1954.

Thalidomide was marketed in 46 countries under different trade names. It was licensed for distribution in the UK and Australia by Distillers Company (Biochemicals), under the brand name Distaval from April 1958 until late 1961. The sedative was promoted as a 'wonder drug' to treat a range of conditions including headaches, insomnia and morning sickness in pregnant women – adverts emphasized the drug's safety using phrases such as 'non-toxic' and 'no known toxicity'. This was misleading as there was ample evidence at that time that Thalidomide had already caused birth defects (limbless babies were born to Chemie Grünenthal employees who had used it), and drugs in that class were known to cause neurological damage and to cross the placental barrier.

"The dark shadow of Thalidomide is still with us. The original catastrophe maimed 20,000 babies and killed 80,000: war apart, it remains the greatest manmade global disaster."

Sir Harold Evans, Editor of the Sunday Times from 1967 to 1981

The physical and psychological damage caused by Thalidomide

Physical damage

The main impairments caused by Thalidomide affect the limbs and are usually bilateral, both arms, both legs, or all four limbs. The most severe impairment is known as phocomelia, a condition where the long bones of some or all limbs are misshapen and where the hands and feet, which can be either, malformed or rudimentary, arise from the trunk. Impairments cover a wide spectrum of limb disabilities ranging from a substantial shortening of the limbs or entire limblessness, to fused fingers. One of the trademark features of Thalidomide is missing thumbs. Thalidomide also affects the development of the eyes and ears, the cardiovascular system, the gastrointestinal tract and kidneys, scoliosis of the back, and the reproductive organs.

Consequential damage

Compounding the damage at birth there is also increasing consequential damage as Thalidomiders grow older. Findings from a national health and wellbeing survey of UK Thalidomiders, undertaken by Firefly for the Thalidomide Trust, show that the health of Thalidomiders is declining more rapidly than that of their peers in the general population (Firefly, 2016). Although this experience is similar in many ways to other people with early onset disability, there are some distinctive Thalidomide-related aspects. In particular, the complex nature of Thalidomide damage and the implications of co-morbidities. Most Thalidomiders report having at least 4 or 5 severe late-onset health issues.

Thalidomiders are now aged 53-58, and in most cases are experiencing the level of wear and tear symptoms that people normally experience in their 80's. The wear and tear comes from using the body in a way different to able-bodied. For example short arms means bending for all tasks using hands, thus putting a much more regular use of, and harsher strain on the neck, shoulders and back.

The same report highlights the increasing prevalence of late onset health issues such as chronic musculo-skeletal pain and wear-and-tear injuries (93% of Thalidomiders reported this). Two-thirds report experiencing neurological symptoms such as numbness or tingling/pins and needles, and the loss of function of hands or fingers, which is likely to be due to the age-related decay of already weak and damaged neural systems. Many are experiencing joint pain, or extensive wear and tear of joints with the need for replacement joints.

Problems with sight and hearing are common as people get older, and Thalidomiders are no different, with two-fifths of UK Thalidomiders reporting worsening sight. However the problem with Thalidomiders is how to correct their sight when they have no ears to hold their glasses on and no arms or hands to put in contact lenses. The report also details over a third of Thalidomiders with hearing/ear problems, and just over a third have problems with dental health (often caused by the consequential damage of using teeth to dress, pick things up, open jars etc). Weight management, hypertension and bladder/continence problems are also now relatively common concerns as the group get older.

Psychological and emotional damage

Psychological and emotional damage affected Thalidomiders and their family members. Some UK Thalidomide babies were abandoned and brought up in care or in hospital. Many marriages broke down, as one or more family members couldn't cope with what had happened to them. There were also stresses and strains caused by the shock, lack of state support, denial of responsibility, and connivance in the cover-up of the scandal.

Many Thalidomiders report they had a difficult relationship with siblings. There was a lot of disruption to family life by frequent hospital visits, the work involved in getting practical and financial support, and the families' 10-year battle for compensation. Given that many Thalidomiders do not have significant brain damage, their experience of being very obviously 'different', with all the exclusion, bullying behaviour and pain of this has been a lifetime experience.

It is therefore no surprise that the Firefly survey (linked earlier in this paper) of UK Thalidomiders found that more than half of them currently have, or have recently experienced, depression and/or anxiety. This is a much higher level than their peer-group age of the UK population in general, but similar to the frequency of mental health problems reported in a recent study of German Thalidomiders (Nieke et al, 2017). Some Thalidomiders have been diagnosed with PTSD (post-traumatic stress disorder), with those who have sought help gaining some comfort from trauma therapies.

Many Thalidomiders have had to give up work or cut back on their work hours and their normal activities, a pattern that has been developing since their early forties. This is thought to be one of the reasons for the group's declining mental health (Glendinning et al, 2016).

Was compensation awarded to UK people born with Thalidomide impairments?

In February 1968, Distillers paid damages to 62 Thalidomide impaired children born in the UK. The amount was widely recognised as an inadequate sum of money and, following a high profile campaign championed by Harold Evans and his Insight Team at the Sunday Times in 1972, an increased final settlement was agreed by Distillers. This included a lump-sum payment for a further

367 children affected by Thalidomide in the UK (on the same basis as the initial 62) together with the establishment of the Thalidomide Trust (into which Distillers paid £20 million) to provide ongoing 'support and assistance' – including annual grants – to all Thalidomiders.

This has proven to be inadequate to cover their needs as they aged, and several times the Thalidomide Trust has had to negotiate an increased financial settlement from Diageo to stop the funds running out (Diageo was the company formed in 1997 by a merger between Grand Metropolitan and Guinness, who had taken over Distillers in 1990). From this fund nowadays, the average payment to a Thalidomider is less than the annual average UK wage, but many rely almost entirely on this for their, and sometimes their family's, general living costs. These inadequate compensatory sums from the Thalidomide Trust have never been enough to allow Thalidomiders to invest properly in their special needs. Adaptations such as foot-steering or adapting a vehicle to be driven from the wheelchair have been too expensive to afford, and houses which had been adequate for younger/more flexible bodies became difficult to live in. Expensive kitchen or bathrooms adaptations were financially beyond the reach of most.

This lack of support, and their 'can-do' approach to daily living, has resulted in Thalidomiders damaging their bodies further by straining themselves in inappropriate and risky ways. This consequential damage is one of the main reasons why a significant proportion of Thalidomiders have been unable to work, especially beyond their 40s. Nowadays, two-thirds of those who did work, have been forced to retire early in their 40s or 50s, or have had to cut down their work hours.

Realising the implications of this, the Thalidomide Trust's National Advisory Council (NAC) conducted a 2-year study into the beneficiaries' extra disability-related costs (NAC report, 2010 – 2012). This showed that a Thalidomider with missing limbs and a range of other damages, needs to spend on average £40,594 per annum on needs directly attributable to Thalidomide disabilities, and that for many, there is still a gap in their ability to invest in their real needs. This figure does not include their general living costs.

Funding from the British government

In January 2010, Mike O'Brien, the UK's Minister of Health, announced a new funding scheme to help survivors cope with their extraordinary changing needs. He also offered what campaigners had been demanding – an apology. The Minister told the House of Commons:

"The Government wishes to express its sincere regret and deep sympathy for the injury and suffering endured by all those affected when expectant mothers took the drug thalidomide between 1958 and 1961,"

"We acknowledge both the physical hardship and the emotional difficulties that have faced both the children affected and their families as a result of this drug, and the challenges that many continue to endure, often on a daily basis." "We know that a lot of thalidomiders have waited a long time for this". (Hansard, 2010)

The British government, through its 4 constituent devolved state Health departments now contributes significantly to the financial needs of UK Thalidomiders. The contribution nearly doubles the amount available to Thalidomiders from their annual allocations from the Thalidomide Trust. For the first time in their lives, it has meant they have been able to afford to carry out significant alterations in their living conditions, such as adaptations to house and garden, vehicle adaptations, and to start to pay towards the many different kinds of other vital support to aid mobility and independence. Whilst the government Health Grant has allowed them to begin to make inroads in the investments needed, it has not been enough to avoid having to make dangerous choices

between capital spend on adaptations and better housing options, and their increasing need for paid personal assistance and other everyday needs. Although the two sources of funding (the Thalidomide Trust Annual Grant and the British government Health Grant) combined do not cover all of Thalidomiders' needs and costs, it is a step in the right direction.

The government Health Grant helps towards allaying concerns for the future

Most UK Thalidomiders are worried about their worsening physical health. This means coping with increased physical disability and pain, and the knock-on effects of deteriorating health on their families, independence, identity and self-esteem. One of the many quotes from Thalidomiders on their personal circumstances in recent reports, linked at the end of this paper:

"My only normal hand is deteriorating badly. I've had 3 operations on it, they can't do anything more. I'm in pain with it nearly all the time. I can't do hardly anything for myself now. I'm terrified. I'm only 55 – how much worse is it going to get? Having one hand I was never disabled but I am now. Luckily I have fantastic children who all automatically do everything for me that's needed. They cut my food up, do up my buttons, zips, and laces, and are amazing but I don't want to be a burden to them. Losing your independence is soul destroying." (Firefly, 2016, page 56)

Due to deteriorating health almost a third of UK Thalidomiders anticipate the need to carry out further home adaptations in the next year, with over 40% expecting a need to move house in the next few years. The most common reasons being to move to a home without stairs, a property that is/can be fully adapted and for a smaller or more manageable garden. Nearly half of the group already have a specially modified car or van, but many need to replace that, or to make new or greater adaptations than previously made.

A Health and Wellbeing survey (carried out for the Thalidomide Trust, by the consultants Firefly (<http://www.thalidomidetrust.org/wp-content/uploads/2016/10/Healthcare-Services-Access-Quality-and-Improving-the-Care-Pathway-for-Thalidomide-Survivors-2017-FINAL-Report.pdf>), has clearly shown that routine NHS services often struggle to provide appropriate diagnosis, treatment and care for Thalidomiders. It found that (in the past five years) nearly two thirds had experienced one or more problems with the quality of and/or access to health services. Consequently many Thalidomiders now rely heavily on self-management of their own health condition. The government Health Grant helps pay for things such as a regular weekly massage, pilates sessions, and private physiotherapy. One in five said their health or wellbeing had improved as a direct result of them spending money on losing weight/healthier eating; medical treatments (e.g. pain medication / surgery); and exercise / therapy (e.g. massage).

"I have enjoyed an improvement in my physical abilities and mobility from having lost a lot of weight. I have also experienced a reduction in my pain levels by exercising regularly and building lots of stretching exercises into my exercise regime. If I stop exercising for any period of time, there is a marked increase in my pain and increase in stiffening of my joints (back, neck, hips)." (Firefly, 2016, page 28)

The government Health Grant can be used for a very broad area of possible expenditure, the principle being that the individual has the flexibility and freedom to spend the money on anything they need within the broad categories of health agreed by the government as being:

- Independent mobility – anything that helps you to lead an independent life, and reduces your vulnerability to harm (vehicles, vehicle adaptations, wheelchairs, taxi-ride etc).

- Home adaptations – anything to allow you to lead a safe and independent life in your own home as far as possible, with subjecting yourself to unnecessary stress or strain, or doing things that could be harmful.
- Communications technology – systems and things to help you to maintain your connection to people and the world at large, and again to protect your body (including sensory organs) from harm and vulnerability.
- Medical treatment costs – can be any kind of therapy, private health care, operations or rehabilitation if not already provided by the NHS.
- Respite – therapeutic breaks for the individual and for their carers.
- Personal assistance – including care in the general sense, but also for a whole range of tasks needed at home or work that you would normally do if you didn't have a disability, but cannot – or would involve putting your body at risk of further damage.
- Social activities – anything to help you get out, or reduce isolation and improve your mental and physical well-being.

This really works for UK Thalidomiders – with increasing difficulties in getting about, needing more personal and domestic help and worsening emotional health all being major areas of worry. It is the precariousness of a way of life lived at its limits, and the need to keep adapting to a rapidly changing situation, usually of decline – that means a regular secured level of financial support is crucial. The government funding allows Thalidomiders to keep up with making new alterations, adaptations, more paid support – to at least try and arrest further declines in health and mobility.

Recommendation:

The Australian government, like the British government, has a role to play in making sure Thalidomiders are given the financial means to support themselves and their chosen way of living. They failed to protect people from being damaged by Thalidomide during the period of 1958 – 1962, and by doing so they have a duty of care to protect and provide for their Thalidomiders now. The British government has stepped up, and it is sincerely hoped the Australian government will do so too.

We strongly recommend that the Australian government provides funding that is flexible and easy to access, allowing Australian Thalidomiders to be in full control of what they spend their money on – like UK Thalidomiders, they know best what they need.

References

Other reports quoted in this paper:

Announcement of the government apology and Health Grant in 2010:

<https://www.theguardian.com/society/2010/jan/14/thalidomide-apology-government>

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From Germany:

Nieke et al (2017). *Mental Disorders in People Affected by Thalidomide - A cross-sectional study of prevalence and psychosocial needs, 2017*. *Dtsch Arztebl Int* 2017; 114(10): 168-74; DOI: 10.3238/arztebl.2017.0168

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From Sweden:

Eckfeldt, A. and Carlsson, G. E. (2008). *Dental status and oral function in an adult group of subjects with Thalidomide embryopathy - A clinical and questionnaire study*. *Acta Odontologica Scandinavica*, 66(5), 300-306.

British government Report, "Deformities caused by Thalidomide," Reports on Public Health and Medical Subjects. : 112, Ministry of Health, HMSO, London, UK, 1964

For further information and access to all the reports referenced in this paper, the UK Thalidomide Trust's website has a number of recent reports that catalogue the health issues and financial needs of UK Thalidomiders.

| <http://www.thalidomidetrust.org/professional-resources-research/research/uk-research/>