

Thalidomide Survivors Snapshot

This is a snapshot and is not designed to be a comprehensive guide. It provides general information about Thalidomide Survivors for NDIA staff and partners and is not intended for external distribution. Each Thalidomide Survivor has been impacted individually and will have their own needs, preferences and experiences that will need to be taken into consideration across the planning process.

In developing this resource, we consulted with Thalidomide Group Australia.

About Thalidomide

Thalidomide was the active ingredient most commonly associated with the medication 'Distaval' and was marketed to pregnant women in the late 1950s and early 1960s, to ease symptoms of morning sickness.

Though pregnant mothers had no way of knowing the effects of Thalidomide, taking just one tablet during the first trimester could cause malformation of limbs, facial features and, significant internal injuries to babies. Today, those adults living with Thalidomide disabilities are aged in their mid to-late 50s. They identify as Thalidomide Survivors.

The impact of Thalidomide





The main deformities caused by Thalidomide included:

- Quadruple absence/deformities/shortness of both upper and lower limbs
- Absence or hypoplasia - underdevelopment or incomplete development of arms preferentially affecting the radius and the thumb
- Thumbs with three joints or no fingers at all
- Defects of the femur and of the tibia
- Defects of the muscles of the eye and of the face
- Absence of the auricles - visible part of an ear, with deafness
- Malformations of the heart, the bowel, the uterus, the digestive tract and the gallbladder; or
- Defects of the spine.

Thalidomide continues to impact each individual differently – in accordance with the level of impairment that occurred in the womb. The individual type of thalidomide malformation depended on the quantity and length of time the Thalidomide was taken by the pregnant mother. While there are common characteristics associated with the deformities, each adult is unique in themselves.

The following impacts are likely still present and may be heightened by the early ageing process, medically acknowledged to be occurring in Thalidomide Survivors around the world:

- Congenital malformation and functional impairment
- Thalidomide induced injuries and impairment
- Premature ageing
- Chronic health conditions
- Psychosocial impact

Myth	Fact
 All Thalidomide babies were born with deformities to their arms or legs.	Babies affected by Thalidomide could have significant injuries to internal organs, without showing an external effects.
 All Thalidomide babies survived.	While it is undeterminable how many babies were affected by Thalidomide, it is estimated that 40% of all thalidomide babies died in the womb or within their first year of life.
 All Thalidomide survivors have an intellectual impairment as well as significant physical disability.	Thalidomide is NOT linked to intellectual impairment or disability.
 Thalidomide is known to be the biggest medical disaster the world has ever seen. It will never be forgotten.	Many doctors today have no idea what Thalidomide is, how it affected the unborn foetus, and how to now treat a survivor.

Common barriers to social and economic participation

Australia currently has around 150 *recognised* Thalidomide survivors. It is likely those numbers *may* increase, should further investigations occur. The relative few numbers have not warranted (until now) specialist Australian medical research – so there has been reliance on international studies.

Research from the UK indicates that most people born affected by Thalidomide have gone on to have happy lives with families and/or a career. However, the wear and tear on their bodies as they get older has become increasingly noticeable. The Thalidomide Trust (UK) has recently researched issues of health and wellbeing with



all of their members and, the results show that two-thirds rate their physical health as the same or worse than the lowest 2% of the general population.

The key health problems noted are:

- pain that can be severe and / or continuous (90% of beneficiaries noted this)
- reduced flexibility and mobility that make it difficult to undertake everyday tasks;
- significant neurological impairment and pain;
- tingling and numbness and,
- poor reduced emotional resilience which in some people may lead to anxiety, depression and suicide ideology.

The cost of specially tailored clothes, prosthetic limbs, wheelchairs and hearing aids/implants has been noted as difficult to cover financially - particularly as many people find they are no longer able to work due to their disability.

Common language and terminology

Don't say	Instead say	Here's why
Thalidomide victim	Thalidomide survivor	Those with the resulting disabilities have actively resolved to 'live' despite the significant impairments.
"You're a Thalidomide baby!"	You're a Thalidomide survivor.	Today, those adults living with Thalidomide disabilities are aged in their mid-to-late 50s.

Engaging with families and carers

The families of Thalidomide Survivors, particularly survivors' parents, spouses and children, live with the effects of what Thalidomide did to the person they love. Parents of Thalidomide Survivors experienced trauma, guilt, and life changing carer responsibilities. The spouses and children of survivors have missed life opportunities and continue to make considerable personal commitments as they provide care and support to their loved one.

Carers may need support and relief and, in particular, may need to take a break from time-to-time to sustain their own wellbeing, their relationships with other family members and friends and their capacity to continue caring.

Taking time off can reduce carers' stress and give them an opportunity to recharge their batteries. It can also assist their capacity to continue to provide quality care. It may also assist participants.



What specific supports might a Thalidomide Survivor need?

Each Thalidomide Survivor is different and the reasonable and necessary funding in their plan will reflect their functional impairment and the support they need to achieve their goals. A range of supports might be considered in determining how best to support Thalidomide Survivors into the future, including:

- Assistive technology
- Home help - assistance with everyday needs, household cleaning and/or yard maintenance.
- Social interactions
- Home modifications
- Vehicle modifications
- Physiotherapists and/or Occupational Therapists
- Clothing alterations specific to the disability needs
- Transport; or
- Supports that result in a break for carers.

How can I tailor a meeting with a Thalidomide survivor?

Most Australian Thalidomide Survivors have remained active members in their local communities and many have not sought disability support services or government payments. Ensure you talk through what mainstream community and government services and programs might be available – ‘you don’t know what you don’t know!’

Many Thalidomide Survivors will require a table for writing and a drink at a meeting.

Some Thalidomide Survivors are no longer able to take physical notes during a meeting. Ensure notes are made available at the conclusion of meetings.

Consider also general preparation, prior to the meeting, during the meeting and at the conclusion of the meeting.

Helpful links for further information

[Thalidomide Group Australia](#)

[The Thalidomide Trust \(UK\)](#)