

# The **Thalidomide** Trust

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Social Care Assessment  
Professional Resource



# The Thalidomide Trust

## What Do I Need To Know About Thalidomide Before Carrying Out An Assessment?

Thalidomide embryopathy is unique and considered a rare condition.

The historical context of thalidomide is important – this is not a genetic condition or an acquired disability. It is vital to know that Thalidomide was a significant scandal in the 1960's.

[Visit our About Thalidomide page for more details](#)

The condition is usually called thalidomide damage and sometimes medically - Thalidomide Embryopathy.

There are a number of terms that are used when referring to someone who was damaged in utero by maternal ingestion of the drug thalidomide, these include:

- **Thalidomide survivor**
- **Thalidomider**

Most people do not like the term ‘**thalidomide victim**’; it is best to ask the client which term they prefer.

## What Was The Impact Of Thalidomide?

Thalidomide caused damage to the developing embryo in utero. The damage caused by thalidomide can include any combination of the following:

**Upper Limb damage** – No arms, arms short above the elbow, arms short below the elbow, hand and wrist damage, missing digits

**Lower Limb damage** – No legs, legs short above the knee, legs short below the knee, hip damage, foot damage

**Missing joints** – Knees, hips, elbows, wrists – in shortened limbs

**Reduced range of movement** – It may not be possible to bend or raise limbs

**Spinal damage**

**Absent or damaged external ears** – May use prosthetic ears

**Damaged internal ears**

**Facial palsy and damaged facial bones** – Small jaw and overcrowding of teeth

**Vision impairment and sight loss**

**Hearing impairment**

**Internal damage** – Bowel, reproductive organs, vascular system, kidneys etc.

**Stomas** – Resulting from anal stenosis and internal damage

**Infertility**

**Pain** – Almost all thalidomide survivors live with chronic pain

**Neurological issues** – Numbness, tingling, pins & needles, loss of grip and strength

**Psychological issues** – Most commonly depression/low mood and anxiety

**Secondary damage** – Arthritis

We differentiate between **upper limb damage** and **lower limb damage** and the terms ‘**short arms**’ and ‘**short legs**’ are acceptable.

Upper limb damage is the most common type of thalidomide damage with 85% of thalidomide survivors having some degree of this.

The Thalidomide Trust is the respected authority on the condition and more information can be found in the website area **For Professionals**.

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## Understanding A Thalidomide Survivor's Point Of View

People born with thalidomide damage have been in the public eye throughout their lives. As children they have been subjected to many investigations and assessments and were objects of interest to medical professionals and social workers. There is an understandable commonly held mistrust of professionals.

As a result, thalidomide survivors have worked hard to disprove the bleak prognoses often given at birth. They can be fiercely independent. They have achieved a level of independence that was not expected at the time and most may not even recognise that their way of day-to-day living would make them eligible for support, as it is so typical and habitual for them.

## Using Sensitivity To Establish Exactly How Daily Tasks Are Undertaken

Therefore, when undertaking an assessment, it is important to understand how a task is completed. Do not just accept at face value if someone says they are able to complete it.

**Thalidomide survivors may have unique ways to complete tasks.** For example those with upper limb damage often use their feet, including making a hot drink using their feet.

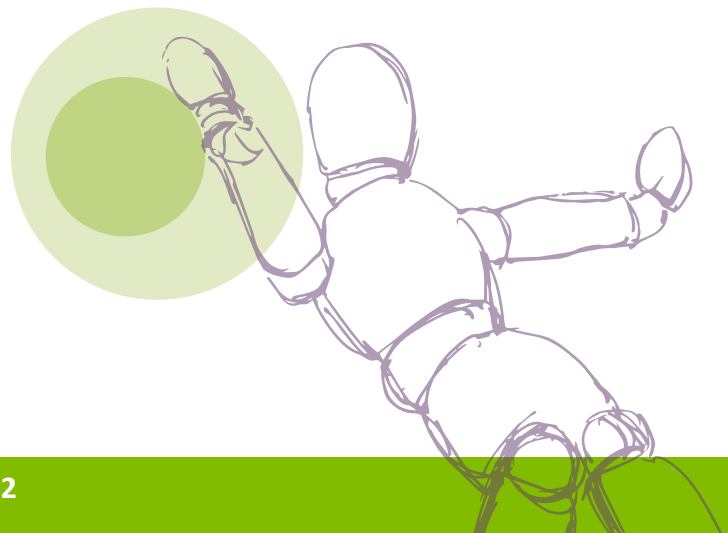
Sensitive questioning skills will enable you to identify how tasks are completed and any risks this may involve. This is particularly important with personal care and toilet routines, which some beneficiaries may feel uncomfortable to discuss.

It's important to recognise that admitting difficulty with a task, may equate to feeling like hard-won independence is being lost. **Please be sensitive to this during your assessment.**

This is particularly the case as all thalidomide survivors are **now aged between 57 and 63** and are having to come to terms with ageing. Evidence shows that the impact of living with thalidomide damage and using their bodies in ways for which they were never intended (using feet instead of hands, living with a very short reach etc) means that **thalidomide survivors are experiencing the challenges of ageing earlier** than most non thalidomide-affected people.

## Consider The Effects On Wellbeing In Addition To Physical Health And Abilities

It is important to consider holistic support. Whilst tasks such as personal care or support to take medication may be obvious, it is often the needs that affect quality of life such as accessing the community or maintaining friendships that have the most impact on wellbeing. Thalidomide survivors experience high levels of social isolation and as a result experience higher levels of anxiety and depression than for an equivalent cohort in the general population. However, it can be harder to identify these unmet needs, especially if the beneficiary has been struggling along without any care and support and has previously been unable to participate as they would want to and has become accustomed to social isolation.



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## Determining Support Needs - Flexibility, Choice And Control

Beneficiaries want to live their lives as independently as possible, and many find a Personal Assistant is the best way to do this. It is not usually practicable to try to break their care and support needs into chunks of time, for example 1 hour a day for personal care, as, like most of us, these needs will vary from day to day depending on their plans, feelings and wishes. Please support them to have dignity, choice and control in their care planning.

## Common Areas Of Daily Life Where Functional Restriction Occurs

### Managing and maintaining nutrition

Thalidomide survivors may have a reduced ability to cut, chop, lift, and stir safely. There is a likelihood of burns due to reduced reach and proximity of hot items to body. They may need to have food cut up or be fed. Some may be unwilling to eat in public or require assistance to do so if they would normally use their feet to eat at home. The risk of falls is increasing if using legs/feet for cooking or eating. Weight management can be an issue due to reduced mobility, pain and low mood.

### Maintaining personal hygiene

Thalidomide survivors may be unable to reach all parts of their body for washing and dressing due to reduced reach, inflexibility, limited range of movement, poor balance and/or pain. They often develop their own methods which may be unsafe and or cause pain and fatigue – for example putting a sponge on the shower wall and rubbing against it. There is a risk of slipping and falling in shower/bath and a high level of fear of this, so even if can bathe alone may need another person to be in the house.

### Managing toilet needs

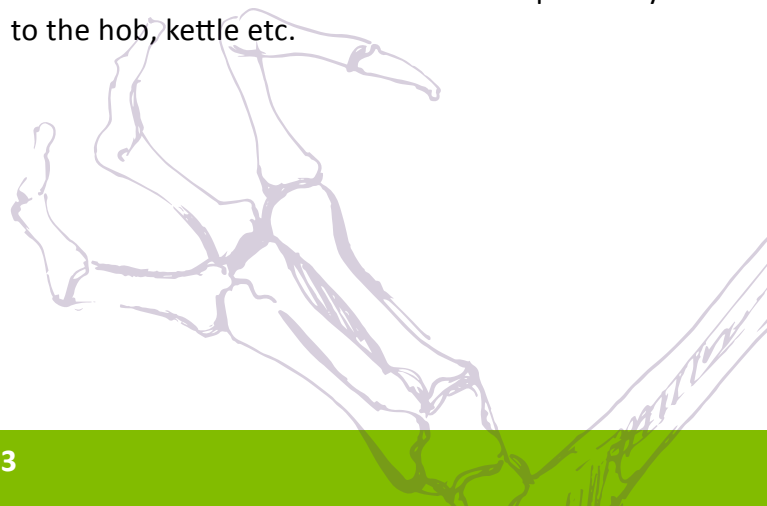
Thalidomide survivors may need support when transferring, cleaning themselves, or need extra space for a prosthesis or wheelchair. They may have an adapted toilet at home. They may also have a lot of difficulty cleaning themselves after an 'accident'.

### Being appropriately clothed

Clothes need to be specially adapted – e.g. shortened sleeves, and easy to wear. Some thalidomide survivors avoid underwear and bras as they are too difficult to manipulate. Belts, buttons, zips cannot be used without help. Thalidomide survivors often choose slip-on shoes or shoes that can be removed easily if feet are used to undertake tasks. If they have leg damage, they will have difficulty transferring and may need to sit on the floor in the shower.

### Being able to make use of the home safely

Thalidomide survivors are often at higher risk of harm because of the coping strategies they use to maintain independence. For example, climbing onto worktops to reach items if they have short limbs. For this group, short upper limbs make breaking a fall difficult, and therefore injuries can be more intense. Many typical aids and adaptations that would be offered, such as grab rails, are unsuitable. Thalidomide survivors also live with chronic pain, so may have to take high strength pain killers which can cause drowsiness. Everyday activities such as cooking carry increased risk of burns or scalds due to proximity to the hob, kettle etc.



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There is an increased risk of unintentional self-neglect, especially with personal care and toileting routines, as thalidomide survivors may decline support due to embarrassment.

The risk of isolation and loneliness is very high and exacerbated by the challenges faced when socializing in the community, as detailed in the paragraphs below.

## **Maintaining a habitable home environment**

If thalidomide survivors have short arms, simple tasks such as cleaning a kitchen worktop or the bathroom can be extremely difficult due to lack of reach. Pain and fatigue can make vacuuming and mopping difficult, and appliances are made for able-bodied people. Tasks such as laundry and changing bed linen can be impossible, or take much longer than they would typically.

Simple home maintenance that an able bodied person may usually do themselves, such as changing a light bulb, putting in batteries or using a screwdriver for a simple task can be difficult or impossible for thalidomide survivors with damaged hands and digits, requiring the help of others, or even paid assistance for routine jobs.

## **Developing and maintaining family or other personal relationships; Accessing and engaging in work, training or volunteering**

Some thalidomide survivors have a hearing impairment as a direct result of their thalidomide damage. It is also a very common feature of thalidomide damage to have narrow ear canals which frequently become blocked with wax, affecting hearing. Inserting and removing a hearing aid is very difficult for someone with short/no arms. Using sign language is also difficult for someone with arm or hand damage.

Sight impairment may result from facial damage and putting on and removing glasses/contact lenses is very difficult for those with short/no arms. Facial disfigurement may also cause speech impairment.

There are high levels of social anxiety and distress as a result of being stared at.

For those with short/no arms, there is a limited ability to gesticulate with hands.

Many thalidomide survivors had interrupted education as a result of repeated surgical interventions and there is some evidence of learning disability and autism amongst the thalidomide group. This has often gone undiagnosed and unsupported because the focus has been on the physical disability and the expectations have been low for some survivors.

## **Making use of community services**

As well as difficulty caused by physical disability, pain and fatigue, there is increasing evidence of mild to severe social phobia and horror of being stared at or photographed which has become more pronounced with the introduction of camera phones and social media. As a result, clients will restrict going out to only where they are known, others may not go out at all and some only go out accompanied. High levels of anxiety and feelings of physical vulnerability can limit thalidomide survivors' willingness to engage with others. For those with speech and hearing impairment there is emotional vulnerability arising from the inability to make themselves understood.

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## Caring responsibilities for a child

Due to their typical age, few thalidomide survivors have dependent children.

## Reading

As all thalidomide survivors were born between 1959 and 1965 they often had a poor educational experience as a result of frequent hospital appointments disrupting their schooling and low expectations of children with such severe disabilities. Holding a book and turning pages is difficult with short arms. It is often not possible to hold a newspaper. Wearing glasses for reading is not always possible for those thalidomide survivors with facial damage and damaged external ears.

## Engaging With Others

### Carers

Many beneficiaries may appear independent, but often they are very reliant on informal carers. As they are aging, the need for this support to be identified, and appropriate respite provided to carers is vital. Additionally, local authorities need to understand the needs of beneficiaries should carer arrangements break down, and support beneficiaries to make emergency plans.

Carers may need to be encouraged to talk honestly about any challenges with their role and may benefit from speaking to you privately.

## Finances

Beneficiaries are in receipt of funding from the Government (the Heath Grant) and receive a compensation payment from the Trust.

Under The Social Security (Infected Blood and Thalidomide) Regulations 2017 (Statutory Instrument 2017 / 870) both income and capital from these payments are disregarded when Social Care financial assessments are completed.

Thank you for taking the time to read this factsheet, we hope it has been helpful in providing some additional insight into living with thalidomide embryopathy. If you would like any further information, please contact the [Thalidomide Trust](#).





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