

Condition Insight Report (CIR)

Thalidomide Embryopathy

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Completed in collaboration with

Thalidomide Trust

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Overview

What is the condition usually called / any abbreviations used?

Thalidomide Embryopathy

Sometimes known as thalidomide damage.

Brief overview of the condition

Thalidomide damage is seen as a rare disease, there are very few experts on its effects in the UK other than The Thalidomide Trust who are highly knowledgeable and recognised as the definitive authority.

What is the generally preferred term for someone with this condition?

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' but it would be best to ask the person you are assessing which term they prefer and then use this throughout the assessment.

Presenting Symptoms

Can include, but not limited to 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**
- **Use of prosthetics**
- **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**
- **Neurological issues** – Numbness, tingling, pins & needles, loss of grip and strength
- **Psychological issues** – Most commonly depression/low mood and anxiety
- Secondary damage – **Arthritis**

Fluctuations



Some aspects of the impact of thalidomide embryopathy are constant – for example absent or shortened limbs, hands and/or feet, missing digits, hearing impairment, sight impairments and facial paralysis have a continuous impact.

Severe and chronic pain and/or fatigue may well be a significant issue as a result of living with a damaged body. Some level of pain or fatigue may be constant. Pain flare-ups may be experienced and mean they will be significantly less likely to carry out daily living activities.

- **Temperature control** – do they experience either hyperhidrosis (excessive sweating) or feel the cold excessively? How often? What does it impact?

Where pain/fatigue are reported think about exploring things like:

- **What level?**
Can they quantify this, do they use a scale and can they describe it? What level of severity? Can they discuss this in this way over what might be a 'typical' day for them?
- **Triggers?**
Whilst exertion is a main trigger what amount of exertion is enough to cause further limitation?
How are triggers managed?

Where there is use of prosthetics:

- How often are they able to wear their prosthesis? If they report variation you need to explore why this is and whether it is a result of sores, blisters, poor fitting, residual limb size variation, component failure, phantom limb pain, and/or generalised limb pain from nerve responses.
- How frequent are any impacting factors including, how long they last, how the symptoms manifest, what functional changes they have during this time?

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY



TIMELY



ACCCEPTABLE
STANDARD



REPEATEDLY



Do they have any symptoms which could cause a safety consideration?

For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

Are they able to repeat a task as often as required? Is this the same every day?

People with congenital malformations usually carry out activities differently which, may now be having a negative impact on their health and can potentially be unsafe, but they may fear the total loss of their independence without doing this. They may understate the difficulty or safety of how they have to manage on a day to day basis.

Depending on the type of congenital malformation(s) will depend on how time is affected when completing activities. Due to the extensive restrictions that can occur, where there is any indication of increased time taken to complete tasks this should be explored in all suitable areas.

Due to the level of pain and fatigue some may experience, it is very likely time may be a factor in the reliability of a task.

Where there are absent or short limbs the individual will have adapted to complete tasks which could include using teeth, knees and feet in conjunction to compensate for reduced range or loss of power/dexterity. Doing this can cause constant impact on their joints and muscles creating pain and fatigue in varying degrees. Asking for support may feel humiliating and as a loss of independence. Explore HOW in detail they are completing tasks.

The complex nature of congenital malformations must also be properly explored. Individuals may not experience good/bad days. Where there is fluctuation in symptoms reported you need to try and establish what is the majority of days for them. Pain and/or fatigue may often develop after an activity and many survivors can only do a task once or have to follow an activity with a corresponding period of rest.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

- The impact of any internal damage that is not apparent to the assessor
- The use of prosthetics: how these are managed and any associated problems
- The levels of pain and fatigue that are experienced, how these vary and impact on ability to carry out tasks of daily living on different days
- How long it takes to carry out each activity when it is done in a unique or adapted way
- The impact of low mood and anxiety on motivation
- The type and regularity of assistance that is provided/relied upon coming from any family or friends. The extent to which this informal care is relied on is often not recognised.

Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?

In general

- **Do not stare**
- **Avoid the term *victim*.** If you need to refer to the condition, ask them what they prefer
- Consider cross-referencing written answers in the context of oral questions
- Creating a safe space for them to be honest about any things they are finding difficult by **appreciating the high level of independence that people have achieved** in an unpatronising manner and acknowledge that you understand the impact of them using their bodies in alternative ways to what is considered 'normal'.



During face to face interactions

- It's ok to ask if a handshake is welcome but **don't assume** it is not possible
- Ask them if there is anything else you can reasonably do to make them more comfortable, e.g. if it is a hot day, offer to open a window or switch on a fan
- If there is water in the room make sure it is within reach of short limbs (don't put things in the middle of the table). If possible provide drinking straws



Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Reduced ability to cut, chop, lift, and stir safely. Likelihood of burns due to reduced reach and proximity of hot items to body. Risk of falls if using legs/feet for cooking or eating.

Remember in PIP...

Can someone reliably cook at waist height? If so, how long can they stand for? Can they safely peel and chop vegetables and lift pans? If utilising a wheelchair, can they safely transfer to cook or do they require assistance? Have there been any incidents in the kitchen?

Activity 2: Taking nutrition

Where there are absent or short limbs the individual will have adapted to complete tasks which could include using teeth, knees and feet in conjunction to compensate for reduced range or loss of power/dexterity. There may be associated MH conditions and there may be a loss of appetite where prompting is required to eat or cognitive restrictions which require support for sequencing the task. Weight management can be an issue due to reduced mobility, pain and low mood. . May need to have food cut up or be fed.

Remember in PIP...

You need to have established the individual's ability to be nourished, either by cutting food into pieces, conveying it to the mouth and chewing and swallowing; or through the use of therapeutic sources. Spilling food, motivation to eat and risk of choking should be explored.

Activity 3: Managing therapy and monitoring a health condition

Pressure sores may result from sitting in a wheelchair and/or from prosthetic use. Some experience difficulty monitoring medical conditions. For those with no arms there may be an inability to measure blood pressure accurately and have blood taken. Monitoring blood sugar can be a problem for those with diabetes. It is not always easy to get medication doses correct for someone with absent limbs. As a result there may be a lot of variation in symptoms from day to day which impacts on activities of daily living. Many pay extensive amounts for their medication to manage their condition.

Remember in PIP...

If someone is regularly managing pressure sores, do they require assistance? If so, how often is this and how long does it take? Do they require assistance to manage their medication or monitor their health condition due to their condition? Can they get medication out of packets unaided?

Functional Impact

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Activity 4: Washing and bathing

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. Clothes need to be specially adapted – e.g. shortened sleeves, and easy to wear. Some avoid underwear and bras as they are too difficult to manipulate.

Remember in PIP...

How are they managing to get in and out of an unadapted bath? Have they had any falls? Do they use any aids? Can they wash their entire body? Do they need assistance to reach certain parts? How long does it take them to wash their entire body? How does this make them feel physically?

Activity 5: Managing toileting needs and incontinence

Transferring, cleaning themselves, needing extra space for a prosthesis or wheelchair, may have an adapted toilet at home. They may also have a lot of difficulty cleaning themselves after an 'accident'.

Remember in PIP...

Can they reliably transfer onto the toilet? Are they safe doing this? Do they use any aids or require assistance? Can they reliably clean themselves? If they have incontinence, can they self manage or do they require assistance?

Activity 6: Dressing and undressing

Clothes need to be specially adapted – e.g. shortened sleeves, and easy to wear. Some avoid underwear and bras as they are too difficult to manipulate. No belts, buttons, zips without help. Slip on shoes or shoes that can be removed easily if feet are used to undertake tasks. Leg damage, will have difficulty transferring and may need to sit on floor in shower.

Remember in PIP...

Explore what management strategies are used to manage any malformations and consider whether aids would help or whether the action would still be unreliable due to one or more aspect of STAR. Remember sitting down is not considered an aid. When they are sat does this help or would they still need support and why is this? Ensure to probe for specific detail about how they complete the task to understand compensation strategies.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating verbally

Some thalidomide survivors have a hearing impairment. It is also a very common feature 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. For those with short/no arms, there is a limited ability to gesticulate with hands.

Remember in PIP...

Do they have any hearing difficulties? If so, how do they overcome this? Do they use aids, do they require sign language or to rely on lip reading? Can they express themselves and make themselves understood?

Activity 8: Reading and understanding signs and symbols

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.

Remember in PIP...

Ability to correct vision should be established. Holding a physical book is not considered. There are specific boundaries for what is considered basic and complex. Ensure to explore for specifics where a restriction is reported to determine if simple and/or complex criteria is met.

Activity 9: Engaging with others face to face

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 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 being unable to make themselves understood.

Remember in PIP...

Cover where specific restrictions are reported how they manage this. Detail of any support provided and whether this support can be provided by anyone or only specific individuals.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

The high levels of depression and low mood may mean that some people make unwise decisions, as a result many thalidomide survivors rely on support from the Trust to manage their money, plan a budget and make financial decisions.

Remember in PIP...

We must explore not only the cognitive ability to manage finances, but also any motivational restrictions reported. Are they motivated to manage household bills? How would they feel if they received a new bill through the post? Can they plan for future purchases? If not, why not?

Activity 11: Planning and following a journey

High levels of anxiety can be present, as a result do not go out alone. Hearing impairments can cause missed announcements and therefore being diverted / getting lost and not being able to ask or understand directions. Sight impairments mean that some thalidomide survivors are completely reliant on help with this aspect of life. **Driving:** often very reliant on a car as their sole means of maintaining independent mobility, as unable to walk any distance or use public transport safely. May still find driving tiring or painful and not be able to drive long distances due to pain or toileting issues. May have adapted car but some are able to use automatic vehicles with electronic controls – e.g. automatic lights, keyless entry, automatic boots and rain sensors.

Remember in PIP...

If someone has a hearing restriction, how does this impact them when out of the home? Could they hear a train announcement on a platform? Could they manage unfamiliar journeys alone? Just because someone is driving, this does not mean they can complete any journey unaided. Furthermore, if anxiety is reported, does this meet the OPD threshold? How does their anxiety manifest? If it meets the threshold, how often can they go out of the home with support? Are these symptoms present on familiar and unfamiliar journeys?

Activity 12: Moving around

Leg damage may cause inability to walk outdoors and reliance on wheelchairs. They may move around on the floor at home by crawling or walking on their hands. This causes pain and stress on the shoulders. Those with short/no arms may be able to physically walk outdoors but this is often limited by pain in the hips and knees caused by overuse of these joints to compensate for upper limb damage. Abnormal gait is common which causes back pain after short periods of walking and balance issues and they may be unable to use usual aids and equipment such as walking sticks due to short arms or poor grip.

Remember in PIP...

You must also explore compensation strategies. Instead of asking about distance in general, use examples specific to them and what they do day to day. You must explore whether any journey discussed is repeatable, where possible how long it takes them, how they feel whilst doing it, and any incidents of note such as falls or injuries in the past 12 months?

Additional reading or other resources

EXTERNAL

- **The Thalidomide Trust Upper Limb Damage Impact Statement** - <http://www.thalidomidetrust.org/wp-content/uploads/2017/03/Upper-limb-impact-statement.pdf>

The Thalidomide Trust PIP case studies:

- <https://www.thalidomidetrust.org/wp-content/uploads/2019/01/Case-Study-1-Upper-limb-and-eyesight-affected-1.pdf>
 - <https://www.thalidomidetrust.org/wp-content/uploads/2019/01/Case-Study-2-Upper-limb-and-back-affected.pdf>
 - <https://www.thalidomidetrust.org/wp-content/uploads/2019/01/Case-Study-3-Upper-limb-affected.pdf>
 - <https://www.thalidomidetrust.org/wp-content/uploads/2019/01/Case-Study-4-Hearing-impaired.pdf>
 - <https://www.thalidomidetrust.org/wp-content/uploads/2019/01/Case-Study-5-Lower-limb-affected.pdf>
 - <https://www.thalidomidetrust.org/wp-content/uploads/2019/01/Case-Study-6-Upper-limb-ear-and-eyesight-issues.pdf>
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- **Watch BBC 2002 documentary on Thalidomide** - <https://www.youtube.com/watch?v=O8ucuLpECNw>

INTERNAL

- Desktop Aid – Activity 12

Version control