

The Thalidomide Trust



Front Line Social Care Worker
Pack

The Thalidomide Trust

This resource pack is designed to provide useful information for a front line social care worker, working as a Personal Assistant (PA), or carer, for the first time with someone who is living with the effects of the drug thalidomide.

It was developed with input from people who have lived with thalidomide damage their entire lives and who have experience of employing paid support. It is intended to provide information that is specifically relevant to the needs and experience of this unique group of people and to improve your understanding of their story and wider context in which you will be working.

The Thalidomide Trust has lots of useful information on our website – www.thalidomidetrust.org and we have a specific section for professionals where you can download more copies of this pack, as well as other resources.

We also have a friendly health & wellbeing team who are always available if you need advice or support on [01480 474074](tel:01480474074)



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About thalidomide

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What is thalidomide?

Thalidomide is a drug that was marketed to pregnant women in the late 1950's and early 60's as a sedative and morning sickness treatment which subsequently caused their babies to be born with disabilities.

'Thalidomide' is not a genetic disorder, or an acquired disability. It is a unique and rare condition usually known as thalidomide damage.

The use and effects of thalidomide caused a huge scandal in the 1960's which is important to remember today.

People damaged by thalidomide in the womb are referred to in different ways, including:

- Thalidomide survivor
- Thalidomider

Most people do not like the term 'thalidomide victim'; it is best to ask which term they prefer.

How many babies were affected by thalidomide?

It is difficult to count the number of babies born with thalidomide damage as many were not carried to full term; some were still born or died very soon after birth. We believe that as many as 100,000 babies were affected by the drug in total with over 10,000 thalidomide babies being born worldwide. Today fewer than 3,000 survive.

Are there any thalidomide survivors still alive in the UK?

There are currently more than 400 people in the UK who were born with thalidomide damage and are recognised as beneficiaries of the Thalidomide Trust

What sort of problems has thalidomide caused?

Thalidomide caused damage to the developing embryo in the womb, which can include any combination of the following:

- **Upper limb damage** – No arms, arms short above the elbow or below the elbow, hand and wrist damage, missing fingers, shoulders that dislocate
- **Lower limb damage** – No legs, legs short above the knee, or below the knee, hip

damage, foot damage

- **Missing joints in shortened limbs** – Such as knees, hips, elbows and wrists
- **Reduced range of movement** – Some people may not be able to bend or raise their limbs
- **Spinal damage**
- **Missing or damaged ears on the outside** – May use prosthetic ears
- **Internal ear damage**
- **Facial palsy and damaged facial bones** – Small jaw and overcrowding of teeth
- **Impaired vision and sight loss**
- **Hearing impairment**
- **Internal damage** – Bowel, reproductive organs, vascular system, kidneys etc.
- **Infertility**
- **Pain** – Almost all thalidomide survivors live with persistent pain
- **Neurological issues** – Numbness, tingling, pins and needles, loss of grip and strength
- **Psychological issues** – Most commonly depression/low mood and anxiety
- **Secondary damage** – Arthritis

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When we talk about thalidomide damage we differentiate between upper limb damage and lower limb damage. It is acceptable to use the terms 'short arms' and 'short legs' when you describe these disabilities

Upper limb damage is the most common type of thalidomide damage and 85% of thalidomide survivors have it to some degree

Do people born with thalidomide damage have children with similar disabilities?

Many thalidomide survivors have had children. Their disabilities are not genetic, so they can't be passed on to the next generation.

What is thalidomide used for now?

Today, thalidomide is used to treat myeloma (a type of cancer that starts in the bone marrow) and Hansen's disease (once known as leprosy). In the UK, there are very tight restrictions on women of child-bearing age being treated with the drug to avoid babies being born with disabilities.

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Living with thalidomide damage now

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Physical health

Many babies born with thalidomide damage have grown up to have fulfilling lives with partners, able-bodied children and jobs they enjoy. However, years of having to compensate for their disabilities by using their bodies in ways that they weren't designed for have taken their toll.

Research shows that thalidomide-affected people experience significantly poorer physical health than non-affected people of similar ages.

The key health problems that people experience are:

- **Pain** – More than 90% of people living with thalidomide damage experience severe and/or continuous pain. Most commonly this is musculoskeletal pain from wear and tear on joints and muscles. Pain can have a severe impact on daily life and the ability to manage independently, as well as on mood and energy levels.
- **Tingling, pins and needles and numbness** – Especially in the hands and fingers, feet and legs. For many people this leads to a loss of strength and grip making it harder to manage everyday tasks safely.
- **Balance and Falls** – As a result of living with pain, weakened muscles and reduced mobility, more and more people living with thalidomide damage are finding their balance is not as good as it was. As a result they may fall over, which can be serious if you have no arms to break your fall. Even if someone has not yet had a fall, they are likely to be terrified of falling because the consequences would be so serious. It is important to understand and agree how to help the person to get up after a fall without causing injury to them or to you.
- **Incontinence** – Because of the age of people living with thalidomide damage, incontinence is an increasingly common experience. It is much harder to react to an urgent desire to go to the toilet if you are unable to get your trousers or underwear down quickly, which may result in accidents, after which it is often much harder to clean yourself up. This can lead to people being anxious about being

far from a toilet and choosing to restrict their activities or avoid going out alone.

Mental health

- **Depression & Anxiety** – People living with thalidomide damage have higher levels of depression and anxiety than people of the same age living without a disability. Just under half report suffering from mental health problems, as well as feeling lonely and isolated.
- **Abuse and Discrimination** – People living with thalidomide damage often have obvious and unusual disabilities. Sadly, this can lead to staring, inappropriate questions or even abuse. People may avoid going out, which increases their feelings of loneliness and isolation.

Ask the person you are supporting how they prefer to handle these situations (whether they ignore them, engage in conversation, or leave the situation) and if you believe that you, or they, are in danger, call 999.

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Daily life

Many people affected by thalidomide rely on adapted cars, motorised wheelchairs, prosthetic limbs or specialised hearing aids or implants. They also often need to have their homes adapted to accommodate their disabilities.

Thalidomide damage impacts people's ability to work as they get older and many thalidomide survivors have had to give up work early.

The disabilities people affected by thalidomide live with vary greatly, so the support they might need in their daily life varies from person to person.

The most common kind of daily support needed specifically in the thalidomide community, as opposed to the wider disabled community are:

- Having surfaces adapted to be much higher or lower than usual, so people can access things using their feet or with short arms
- Driving vehicles with adaptations, such as foot steering
- Wash/dry toilets
- Requirement for personal things e.g. food or drink placed much closer or further away than usual
- Needing to get clothing tailored to fit limb length, or only being able to wear certain types of clothes – for example without buttons or fastenings
- Using segways or specially adapted wheelchairs to move around
- Needing support with personal care for areas of the body they cannot physically reach.

This list is not exhaustive and every person is different!

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Working with someone who lives with thalidomide damage – etiquette do's and don'ts

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Shaking hands

When you meet someone with short arms it is usually a good idea to wait and see if they offer their hand for you to shake rather than offering them your hand first. Some people with upper limb damage prefer to shake hands and some with no obvious upper limb damage prefer not to, it's a personal thing.

Think about reach

If you're supporting a person having meals or drinks, think carefully about where to place items on the table; closer to the edge is normally better. People with upper limb damage may need items put on tables closer to their feet, face or shoulders depending on how they prefer to pick things up. People with lower limb damage may be less able to reach for things – so will need them placed closer to them. Those with eye damage may need things put at a specific angle to them so they can see them better or know that they are there. Always ask what their preference is when you first work with them.

Ask don't assume

People living with thalidomide damage have often been fiercely independent throughout their lives and can carry out many daily tasks that may appear unfeasible before you get to know them. With this in mind, you should always ask whether they need help with something before offering support and accept it if they refuse, even if it looks like they are struggling.

For example, don't assume that someone can't hold a cup. You would be surprised how many ways a cup can be held even when there's hot tea in it!

Old habits die hard

Many people have had to adapt to their disability in unusual or old-fashioned ways (using outdated prosthetics, for example, or using spoons to push buttons rather than more modern tools). They are often aware of newer technology but choose not to use it as they are comfortable with what they already have. It can be helpful to ask the person you're working with if they know about the other options, but if they are clear that they don't want to explore these, you should respect their choice.

Respect risk

Some people carry out every-day tasks in a way that appears "unsafe" (such as pouring a kettle with their bare feet, or sitting on the counter to do the washing up). However, this is often the only way that they can do these things independently. The vast majority of people have the capacity to decide whether to carry out a task in a "risky" way, or not – and you should respect their choices as long as you are not being asked to do things in ways that you feel may put **you** at risk

Family

Be mindful that relationships with parents and family, especially mothers, may not have been easy, so comments like "your mum would be proud" or similar may not be met with the reaction you might expect.

Best foot forward

Don't be surprised if someone with shortened arms and/or legs, doesn't have shoes on and use their feet to hold things or manage certain tasks.

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Hearing and signing

Someone with partial or no hearing and upper limb damage may not be able to make British Sign Language (BSL) signs in the “usual” way and may communicate using altered versions. This can be difficult for people who don’t know them to understand, even if they are fluent in BSL.

Also, those who use BSL will have been using it for some time so may use signs that are “out of date” or “old fashioned”. If someone uses a sign you don’t recognise, it may be an older version of a sign.

Be prepared for it to take a while to learn the unique way people sign. Be patient and ask the person to slow down or repeat signs if you need them to.



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Working with someone
who lives with thalidomide
damage – Top tips for
helping with finances

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Helping with money

There are a variety of ways that you may need to help the person you care for with managing their money. You could be asked to help them keep on top of bills and paperwork withdraw cash from the bank, go shopping on their behalf, or order items online.

However experienced you are, this is a high risk area for you and the person you work with, so always respect the trust they have invested in you, and protect yourself. The key to this is record keeping.

If you need advice talk to us at the Thalidomide Trust. We have developed some useful guidance and a formal process you can use to help people manage their money – for example many people use a specific pre-paid card that can loaded with the required funds.

Keeping good records

It is important that you keep records of all money you receive or spend on behalf of the person you are caring for. This will help to avoid any misunderstandings.

It's also essential to keep accurate records; to protect you, as the support provider, and to safeguard everyone involved. We recommend you set up a financial records file using an A4 ring binder with subject dividers and create the sections similar to those below to log, record and file evidence of expenditure:

| | |
|-------------------|--|
| Section 1: | Summary of regular monthly bills and monthly direct debits (e.g: a summary of repeat expenditure such as gas, electric, mobile phone, insurances, water, council tax, subscriptions, sky, broadband, BT etc. etc). |
| Section 2: | Maintain an expenditure log for all other ad-hoc expenditure which isn't from Section 1 (e.g: food shopping, general shopping, orders and other purchases). |
| Section 3: | Maintain all receipts from the expenditure logged in Section 2. File and number the receipts in a sequential order (e.g.: 1,2,3,4,5,6), and log the receipt number on the expenditure log. This makes it easier to cross reference the records being kept. |
| Section 4: | File all monthly bank statements for the account being used. |

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Do's and don'ts when helping with finances

- Don't use your own money or bank card to purchase items, and then get the money reimbursed. This can soon become complicated and may lead to mistakes.
- Don't buy shopping for yourself in the same transaction. It is too easy to mix up shopping costs.
- Don't collect rewards and vouchers (e.g., Boots Advantage points, Tesco Clubcard points) in your name on someone else's shopping. Similarly, don't pay using your own 'cashback' card for the goods.
- Don't buy yourself gifts using your client's money, even if they are insistent. It could cause problems in the future
- Don't ask to borrow money.
- If you're using cash, keep it separately to your own money to avoid any mix-ups.
- With payments becoming contactless, you rarely need pin numbers. Do not write a pin number down or share it with anyone else.
- Do not save someone's card to 'Apple Pay' 'PayPal' or other electronic systems on your own devices; the possibility of accidentally using it is too great.
- Do not use your own devices to order things for your employer online. Your device will often remember card details, making you more likely to use them accidentally.
- Always maintain confidentiality about finances – you may put someone at risk.
- Do ensure you have clear instructions about what you are asked to buy, such as a shopping list, and always keep receipts, or other proofs of purchase.
- Do ask if you are unclear about what you are being asked to do, and don't be afraid to say you cannot complete a financial task if you feel it is inappropriate for your role.
- If you help with online banking and bill payment, only do this on the person's own devices when they are present. Do not save log-in details on your own device, and do not access them out of work hours or without the person present.
- Do seek advice and support if you are concerned that the person you work with is being financially exploited. You can speak to us at the Thalidomide Trust in confidence. This is not an unusual occurrence, and it is better to err on the side of caution.

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Professional boundaries

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Professional boundaries

Positive relationships between you and the person you are working for are key to doing a good job. The PA's who work with beneficiaries tell us how rewarding they find their role and how much they value and enjoy their work and the friendships that they develop with the person they support.

Developing these relationships takes time and work and may feel very similar to other friendships or relationships you have outside work and indeed over time close bonds are likely to develop – that is what makes the role so rewarding.

However at times this may cause uncertainty about how to carry out your roles and responsibilities and this section is intended to help you manage that.

Professional boundaries can be described as the 'boundary between what is acceptable and unacceptable for a professional both at work and outside work'. It is important that you make sure these boundaries are respected.

It can be hard to maintain professional boundaries, especially if you are new to the career of care work, but it is crucial to understand the difference between personal and professional relationships. Often when working alongside someone it may be that you feel a friendship has developed (and it often will do) but it is important to remember the relationship has a work purpose, which is to promote the wellbeing of the person you are working for.

Professional boundaries apply to all aspects of your relationship and to all forms of communication, including social media. People who get into trouble around boundaries have often blurred the boundaries between their personal life and professional life. When professional boundaries become blurred it can make it problematic to address any issues that arise.

It is your responsibility to seek support and take sensitive action if you feel the person you are caring for misreads or becomes confused about your relationship. You can always talk to someone at the Thalidomide Trust if you have concerns about this.

Some behaviours will clearly breach acceptable boundaries and may also break the law. The consent of the person you are caring for is never a defence for any of these practices.

The most obvious examples of these include:

- Any form of sexual contact
- Causing physical harm or injury
- Making aggressive or insulting comments, gestures or suggestions
- Seeking information on personal history where it is neither necessary nor relevant
- Watching someone undress where it is unnecessary
- Sharing your own private or intimate information where it is unnecessary
- Inappropriate touching, hugging or caressing
- The use of illegal drugs or other substances
- Concealing information, for example, not reporting incidents and concerns, safeguarding issues, not completing records, colluding with criminal acts

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- Acceptance of gifts and hospitality in return for better treatment
- Spreading rumours or hearsay
- Misusing money or property
- Encouraging dependence or reliance for your own gain
- Providing forms of care that will not achieve the planned outcome
- Providing specialist advice or counselling where you are not qualified to do this
- Trying to impose own religious, moral or political beliefs on an individual
- Failing to promote dignity and respect



06

Glossary of terms you may come across

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Amelia Congenital absence of one or more limbs.

BAHA A bone anchored hearing aid (BAHA) is similar to other hearing aids, but instead of being inserted into the ear canal or held behind the ear, it is attached to a soft band worn on the head or fixed to a metal implant inserted into the skull. (Great Ormond Street 2023)

Beneficiary A person who has been accepted by the Thalidomide Trust as having damage caused by thalidomide

Bilateral Affecting both sides of the body

Health & Wellbeing Coordinator A qualified health or social care professional who works for the Thalidomide Trust

HNA A conversation with someone from the Thalidomide Trust that takes place in the beneficiary's home approximately every 3 years

Medical Adviser A qualified Doctor who works for The Thalidomide Trust

Personal assistant Someone employed directly by a beneficiary to provide care and support services.

Phocomelia A rare birth defect that can affect the upper and/or lower limbs. In people with this condition, the bones of the affected limb are either missing or underdeveloped. The limb is, therefore, extremely shortened and in some cases, the hand or foot may be attached directly to the trunk.

Thalidomide Trust The organisation set up to provide support to people damaged by thalidomide distributed in the UK

Unilateral Affecting one side of the body

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