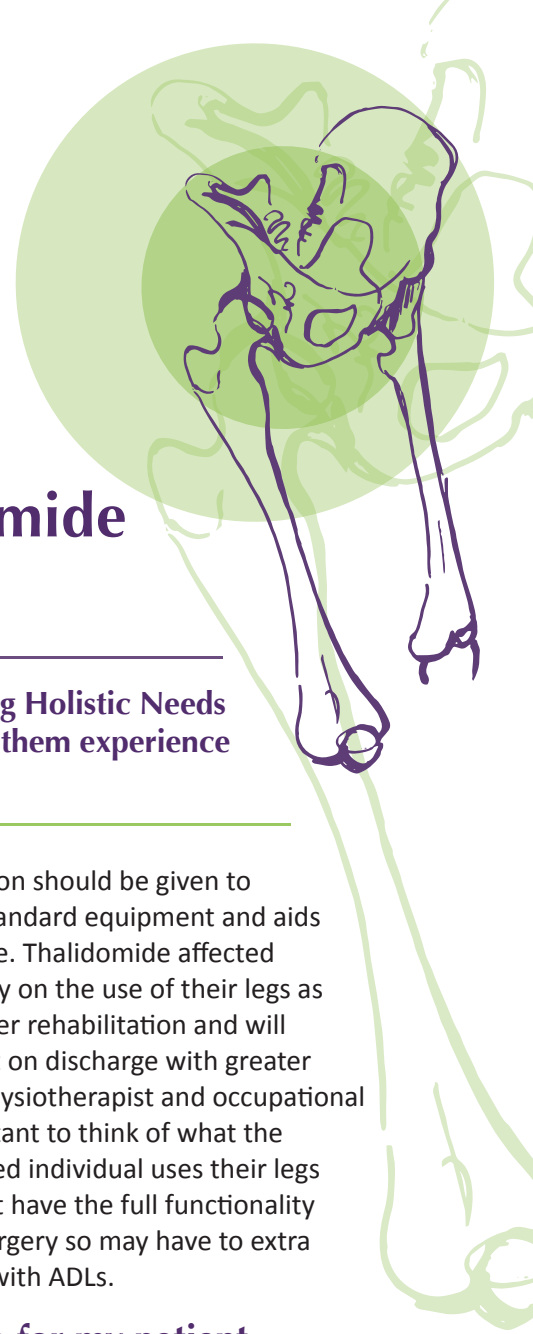


# The Thalidomide Trust



## Why does my patient with Thalidomide Embryopathy experience hip pain?

Many thalidomide affected individuals complain of hip pain. Ongoing Holistic Needs Assessments performed by the Thalidomide Trust reveal that 40% of them experience hip pain and the number is rising.

There are a number of underlying reasons for this including:

- Original damage to the hips caused by thalidomide predisposing the joint to early arthritis
- Overuse of the hip joint when legs are used as arms with someone who has upper limb shortening, again predisposing to arthritis
- Reduced muscle strength and joint malalignment are biomechanical risk factors for OA developing<sup>1</sup> which are common in thalidomide affected individuals.

### Anatomy

Thalidomide affected individuals may display some of the following anatomical features<sup>2,3</sup>:

- The hip joints may have been dislocated at birth
- The hip joint may be hypoplastic/dysplastic or, in rarer cases, completely absent
- Leg length discrepancies

### Specific issues to consider

If the legs are used as replacement arms, then a greater range of movement may need to be retained at the hip joint. This problem can be addressed by using a larger replacement ball and therefore referral to a surgeon with experience of treating thalidomide affected individuals is important. Some thalidomide affected individuals will require a custom made joint replacement. A special orthopaedic hospital such as the Royal National Orthopaedic Hospital is an appropriate choice due to the complex nature of the anatomy and the risk of complications.

Special consideration should be given to rehabilitation as standard equipment and aids may not be suitable. Thalidomide affected individuals who rely on the use of their legs as arms can face longer rehabilitation and will need extra support on discharge with greater input from both physiotherapist and occupational therapy. It's important to think of what the thalidomide affected individual uses their legs for as they may not have the full functionality they had before surgery so may have to extra help in the future with ADLs.

### What can I do for my patient with hip pain?

Early investigation and referral is particularly important to maintain function and preserve independence for people living with a disability which already limits their functionality and because the normal clinical pathway may not be appropriate for them.

#### Investigation

X-rays can demonstrate the degree of arthritis and degree of thalidomide damage to the joint.

#### Referral

Physiotherapy can be very useful and, as all beneficiaries of the Thalidomide Trust receive a Health Grant to meet the additional costs associated with their disabilities, there is often the option for this to be paid for privately.

Steroid injections can be useful to reduce pain whilst physiotherapy is undertaken to strengthen the muscles around the joint. This can be a particularly

useful option for thalidomide affected individuals who are reluctant to undergo surgery or where surgery needs to be delayed.

We would recommend an early orthopaedic opinion from a specialist with the expertise to help.

Despite the hip joint potentially being smaller and more complex than usual, a number of thalidomide affected individuals have gone on to have successful hip replacements. The majority have been seen by those surgeons who are hip revision specialists, both adept at performing a hip replacement in someone with unusual anatomy but also who would have the appropriate experience should the hip need further surgery.

## What self management strategies could I recommend?

- Massage therapy can help loosen tight muscles or work on muscle spasms and provide temporary pain relief<sup>4</sup>
- Some thalidomide affected individuals report benefit from heat pads and hot tubs
- Weight loss can help improve general mobility
- Pacing – breaking down tasks into smaller chunks of time and stopping before the pain comes on. The Thalidomide Trust has produced some information on pacing here <https://www.thalidomidetrust.org/pacing-for-pain/>

## How can the Thalidomide Trust help?

The Thalidomide Trust can assist with recommendations of specialists who have the appropriate expertise and experience of treating thalidomide affected individuals with hip pain.

If a beneficiary needs referral to secondary care for assessment and you are facing prolonged NHS waiting lists and/or the need is urgent, the Thalidomide Trust can assist in making a private referral which can generally be funded from their Health Grant (specific funding allocated to cover additional costs associated with their thalidomide disabilities).

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Whether you would like general advice or would like to discuss a specific patient, you can speak to one of the **Thalidomide Trust's Medical Advisers on 01480 474074.**

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<sup>1</sup>Guilak F. Biomechanical factors in osteoarthritis. *Best Practice & Research Clinical Rheumatology*. 2011;25(6):815-823.

<sup>2</sup>Vargesson N. Thalidomide-induced teratogenesis: History and mechanisms. *Birth Defects Research Part C: Embryo Today: Reviews*. 2015;105(2):140-156.

<sup>3</sup>Smithells R, Newman C. Recognition of thalidomide defects. *Journal of Medical Genetics*. 1992;29(10):716-723.

<sup>4</sup>Boyd C, Crawford C, Paat C, Price A, Xenakis L, Zhang W. The Impact of Massage Therapy on Function in Pain Populations—A Systematic Review and Meta-Analysis of Randomized Controlled Trials: Part II, Cancer Pain Populations. *Pain Medicine*. 2016;17(8):1553-1568.

