

# The Thalidomide Trust

## Why does my patient with Thalidomide Embryopathy experience neck and spinal pain?

Neck and spinal pain are very common in thalidomide affected individuals. The Thalidomide Trust's own research reported that 72% of them had back problems and 55% had neck pain or loss of movement<sup>1</sup>.

Furthermore, data from ongoing Holistic Needs Assessments performed by the Thalidomide Trust shows that the vast majority (92%) have some neck or back pain, or both.

The causes are multifactorial and may be functional, muscular/structural or neuropathic.

There are a number of underlying reasons for this including:

- Original thalidomide damage to the spine means an increased likelihood of arthritis<sup>2</sup>
- People with short arms develop poor posture as they try to compensate for reduced reach, which can lead to shoulder, neck and back pain
- Thalidomide affected individuals are more likely to overuse the neck to compensate for a short reach, making arthritis more likely
- Hemi vertebrae and anterior fusion of the vertebrae can reduce flexibility of the spine
- Compression neuropathies are more common in thalidomide affected individuals versus the general population<sup>3</sup>

### Anatomy

Thalidomide affected individuals may display some of the following anatomical features<sup>4,5</sup>:

- Hemivertebrae and anterior fusion of the vertebrae
- Malformations of the intervertebral disc
- Foraminal narrowing
- Scoliosis
- Spina bifida occulta

### Specific issues to consider

Asymmetrical leg lengths in thalidomide affected individuals may exacerbate back pain.

### What can I do for my patient with neck and spinal 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. In addition, the normal clinical pathway may not be appropriate for them.

#### Investigation

Thalidomide affected individuals may need magnetic resonance imaging (MRI) of the spine at an early stage, particularly if they have progressive myelopathy, radiculopathy or intractable pain. Some hospitals such as the Royal National Orthopaedic Hospital may also use a SPECT-CT to image the spine.

Nerve conduction studies may also need to be performed to investigate paraesthesia<sup>6</sup>, but these will be ordered by secondary care in most circumstances.

#### Medication

Neuropathic agents can be helpful, although the risk of falls should be taken into consideration as thalidomide affected individuals with upper limb damage may be unable to break a fall if they become dizzy and lose their balance.

#### 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.

Physiotherapy can be helpful for the following reasons:

- Helping to strengthen the core muscles, reduce muscle tension and spasm, correct asymmetrical muscle loading and improve flexibility
- It can also identify unequal leg lengths that can be an exacerbating factor in those with back pain and orthotics can be considered



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- Physiotherapy can also be helpful in preventing falls by strengthening the core and legs, helping balance, in addition to learning how to fall more safely and to get up from a fall<sup>7,8</sup>

Please see our physiotherapy case study here:

<https://www.thalidomidetrust.org/physiotherapy-professionals/physiotherapy-video-case-study/>

We would recommend an early orthopaedic opinion from a specialist with the expertise to help. Many thalidomide affected individuals are seen at the Royal National Orthopaedic Hospital (RNOH) or the National Hospital for Neurology and Neurosurgery – both specialist centres used to seeing the complex needs and anatomy they can present with, as well as being able to provide appropriate rehabilitation post-surgery.

Some thalidomide affected individuals have been told there aren't surgical options available to them but who have then gone on to have successful spinal or neck surgery at one of these specialist centres, so choosing an experienced surgeon is imperative.

Examples of the types of surgery performed include complex decompressive surgery including cervical discectomy and fusion, which has been successful in relieving symptoms, along with interventions such as epidural injections or facet joint injections.

Please see one of our case studies below where neck surgery has been life changing:

<https://www.thalidomidetrust.org/neck-surgery-success>

## What self management strategies could I recommend?

- Maintaining a correct posture is important. Pilates and the Alexander technique can be helpful with this
- Utilising personal assistants or family members to perform tasks that thalidomide affected individuals find difficult rather than putting their body in unusual postures to do these tasks
- Massage therapy can help loosen tight muscles or work on muscle spasms and provide temporary pain relief<sup>9</sup>
- Maintaining a healthy weight is important as with weight gain comes loss of independence and flexibility
- Exercise can be helpful in maintaining muscle mass and flexibility, but can be challenging for thalidomide affected individuals. Pilates is recommended and can be adapted for most degrees of disability. Prior to

commencing exercise, a physiotherapy assessment may be required to correct any leg length discrepancy so exercise can be performed safely

- Some thalidomide affected individuals report benefit from heat pads, hot tubs and acupuncture
- Electromagnetic stimulation (EMS) pads on the neck can strengthen muscles<sup>10</sup>
- Some thalidomide affected individuals also find TENS machines helpful
- 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 neck and/or spinal 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 each individual to cover additional costs associated with their thalidomide disabilities).

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.**

<sup>1</sup>Newbronner E, Glendinning C, Atkin K, Wadman R. The health and quality of life of Thalidomide survivors as they age – Evidence from a UK survey. PLOS ONE. 2019;14(1):e0210222.

<sup>2</sup>Jahani S, Daielsson A, Ab-Fawaz R, Hebelka H, Danielson B, Brisby H. Degenerative Changes in the Cervical Spine are More Common in Middle-aged Patients with Thalidomide Embryopathy than in Healthy Individuals. Global Spine Journal. 2016;6(1\_ suppl):s-0036-1582790-s-0036-1582790.

<sup>3</sup>Nicotra A, Newman C, Johnson M, Eremin O, Friede T, Malik O et al. Peripheral Nerve Dysfunction in Middle-Aged Subjects Born with Thalidomide Embryopathy. PLOS ONE. 2016;11(4):e0152902.

<sup>4</sup>Smithells R, Newman C. Recognition of thalidomide defects. Journal of Medical Genetics. 1992;29(10):716-723.

<sup>5</sup>Edwards D, Nichols P. The Spinal Abnormalities in Thalidomide Embryopathy. Acta Orthopaedica Scandinavica. 1977;48(3):273-276.

<sup>6</sup>Nicotra A, Newman C, Johnson M, Eremin O, Friede T, Malik O et al. Peripheral Nerve Dysfunction in Middle-Aged Subjects Born with Thalidomide Embryopathy. PLOS ONE. 2016;11(4):e0152902.

<sup>7</sup>Sherrington C, Tiedemann A. Physiotherapy in the prevention of falls in older people. Journal of Physiotherapy. 2015;61(2):54-60.

<sup>8</sup>Morrison D. Poor balance, bilateral upper limb phocomelia, no previous exercise: a challenging combination for fall prevention in a middle-aged thalidomide survivor. BMJ Case Reports. 2020;13(1):e231345.

<sup>9</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.

<sup>10</sup>Adams V. Electromyostimulation to fight atrophy and to build muscle: facts and numbers. Journal of Cachexia, Sarcopenia and Muscle. 2018;9(4):631-634.