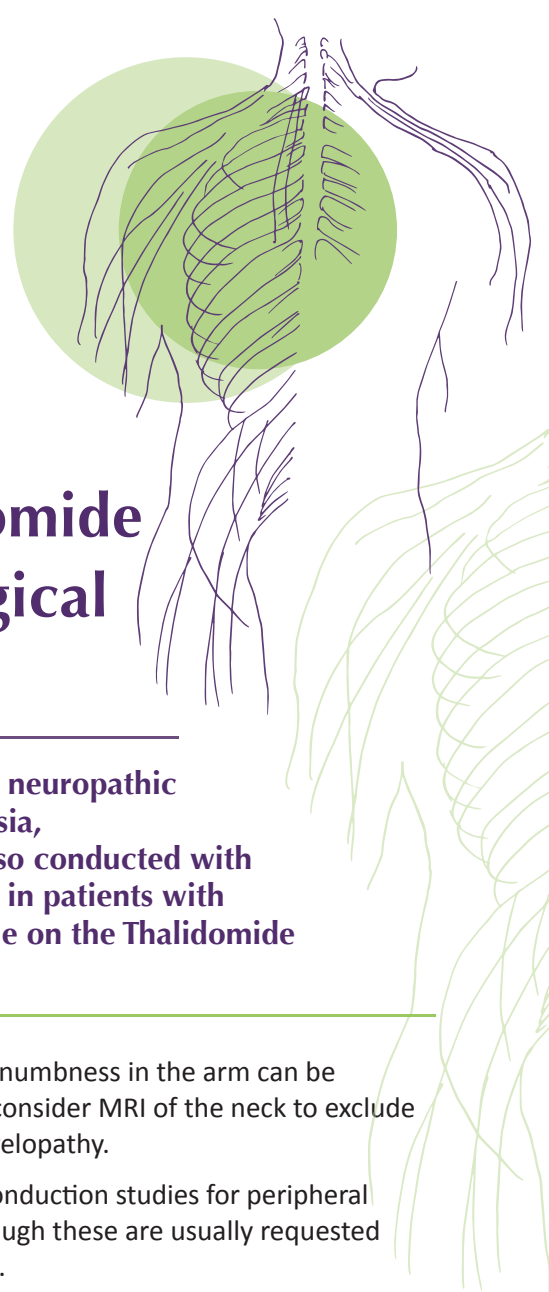


# The Thalidomide Trust



## Why does my patient with Thalidomide Embryopathy experience neurological symptoms such as paraesthesia?

A significant proportion of thalidomide affected individuals report neuropathic symptoms with over half reporting that they experience paraesthesia, according to the Thalidomide Trust's own survey<sup>1</sup>. Research was also conducted with Imperial College, London to look at the peripheral nervous system in patients with Thalidomide-induced limb damage<sup>2</sup>. A copy of the study is available on the Thalidomide Trust's website.

This study found that a very high proportion (90%) showed evidence of nerve compression. It also showed that 15% of study participants had a myelopathy of which surgery was beneficial in around 10% and, in addition, 5% had a lumbar radiculopathy.

### Anatomy

Thalidomide affected individuals may have the following anatomical features:

- Thalidomide damaged joints, due to the unusual anatomy, are more likely to compress nerves
- Thalidomide damaged joints which are more likely to have early arthritis, such as in the cervical spine<sup>3</sup>, meaning compression neuropathies are more likely

### Specific issues to consider

Be vigilant for myelopathic symptoms e.g. progressive upper and lower limb motor and sensory deficit and bladder or bowel dysfunction.

### What can I do for my patient with these symptoms?

#### Investigation

A number of investigations should be considered<sup>2,4</sup>:

Consider screening for B12, folic acid levels, thyroid function and a fasting glucose on an annual basis, although venepuncture can be difficult due to the abnormal vasculature.

Paraesthesia and numbness in the arm can be multifactorial so consider MRI of the neck to exclude radiculopathy/myelopathy.

Consider nerve conduction studies for peripheral neuropathy, although these are usually requested in secondary care.

#### Medication

Neuropathic agents can be helpful although the risk of falls needs to be considered as a potential side effect. This is because thalidomide affected individuals with upper limb damage may be unable to break their fall if they become dizzy and lose their balance.

#### Referral

Early referral for surgical decompression e.g. for carpal tunnel surgery, if clinically indicated. Referral to a local neurosciences or pain service with the appropriate expertise may also be appropriate.

For those with symptoms consistent with nerve compression from the spine/neck, thalidomide affected individuals would benefit from referral to a spinal surgeon for assessment. A centre such as the Queen's Hospital for Neurology and Neurosurgery or the Royal National Orthopaedic Hospital are well placed to see the complex anatomy that thalidomide affected individuals have. They are also able to provide comprehensive rehabilitation should surgery be needed, with appropriate occupational therapy and physiotherapy.

## What self management strategies could I recommend?

- 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 compression neuropathies or neurological symptoms.

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 the individual's 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>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>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>3</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>4</sup>Thalidomide Trust. Lay interpretation of the Peripheral Nerve Study. Available from <https://thalidomidetrust.org/wp-content/uploads/2016/05/Nerve-Study-Lay-Summary.pdf>