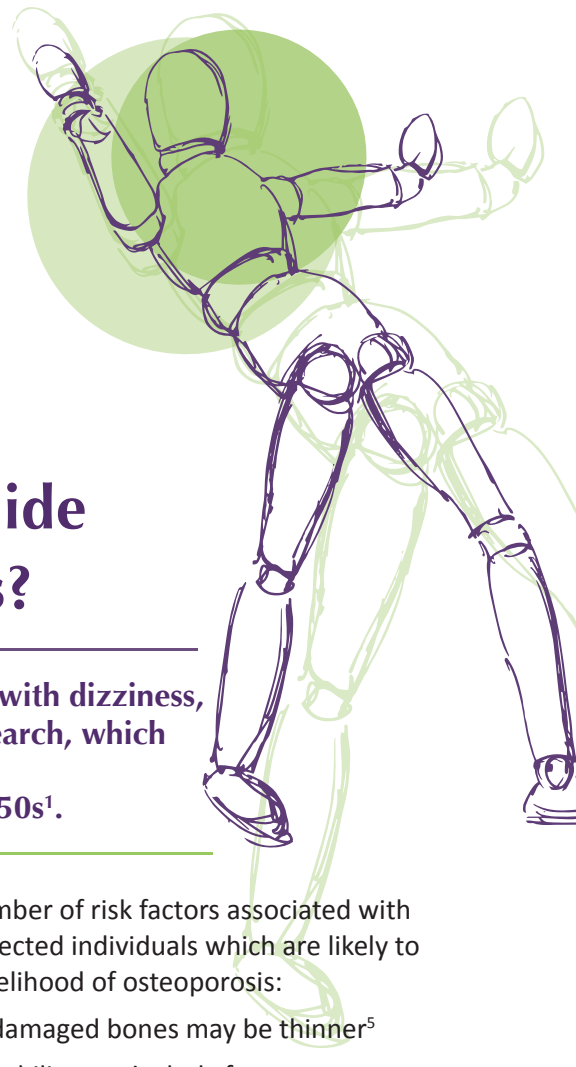


# The Thalidomide Trust



## Why is my patient with Thalidomide Embryopathy more at risk of falls?

Thalidomide affected individuals are frequently reporting issues with dizziness, balance and falls, and this was confirmed by the Trust's own research, which showed one third of respondents reported falls since childhood, but over a half reported they had started to fall in their 40s and 50s<sup>1</sup>.

There are a number of underlying reasons for this including that thalidomide affected individuals are more likely to have:

- An unequal leg length<sup>2</sup>
- Have arthritis and/or chronic pain<sup>3</sup>
- Neuropathic weakness or paresthesia<sup>4</sup>
- Eye sight complications from thalidomide damage<sup>5</sup>
- Loss of muscle mass and strength from lack of exercise

### Anatomy

The aetiology is likely to be multifactorial, but as we know thalidomide in utero affected development of the structures of the ear, it is likely that undiagnosed congenital abnormalities of the inner ear play some part in increasingly poor balance.

### Specific issues to consider

As the majority of thalidomide affected individuals are upper limb affected with a short reach, they may not be able to stop themselves should they fall, therefore they are at greater risk of further disability with a greater need for social care if they do fall.

Falls can have a profound effect on an individual and fear of falling can cause profound psychological distress. In addition, loss of confidence can lead to further limiting of activity which in turn can accelerate further muscle loss.

There are a number of risk factors associated with thalidomide affected individuals which are likely to increase the likelihood of osteoporosis:

- Some of the damaged bones may be thinner<sup>5</sup>
- Reduced immobility particularly for wheel chair users
- A higher than average number smoke; 25% of thalidomide affected individuals smoke, according to the Thalidomide Trust's data, versus 14% of aged matched people in the general population<sup>6</sup>
- Most females within the group are post-menopausal

It may therefore be appropriate to consider a DEXA scan assessment with subsequent scans dependent on individual risk and perform a falls risk assessment.

### What can I do for my patient who is at risk of falls and/or reporting dizziness?

#### Investigation

Reversible or treatable causes should be looked for. This may include:

- Reviewing any medication that cause postural hypotension
- Blood pressure measurement, which may need to be done in the leg (please see our separate guidance on taking blood pressure in the leg).
- A visual assessment by an optician
- Neurological assessment, ECG and echo if indicated

## Referral

Physiotherapy assessment would be recommended to help increase muscle strength and for balance training, but also to assess possible leg length discrepancies and they can also show thalidomide affected individuals how to “fall safely” and how to get up safely after falling<sup>7</sup>. Physiotherapists may also suggest use of a walking aid or stick.

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 physiotherapy to be paid for privately.

Thalidomide affected individuals are likely to have multiple risk factors for falls so we would strongly suggest early referral to a local falls clinic, even if they are out of the typical age range that the fall clinic usually accept.

## What self management strategies could I recommend?

- Suggest removing hazards in the home such as loose rugs or wires, wearing supportive footwear and making sure the home is well lit.
- Recommend exercises such as Physiotherapy led Pilates to help balance and strengthen the legs and core, and Tai Chi which can also help to improve balance.
- Consider recommending or prescribing Vitamin D supplements, especially if the individual is house-bound due to immobility, social phobia/severe anxiety or if chronic pain is present.

Please remember that loss of balance and falls can cause significant psychological distress. This can be short term following an embarrassing fall leaving them feeling helpless and humiliated, whilst others may suffer longer terms effects with anxiety which may cause them to fear going out.

## How can the Thalidomide Trust help?

The Trust have developed information on falls which can be accessed here;

<https://www.thalidomidetrust.org/health-and-wellbeing/health/falls-and-balance-awareness/>

We can also assist in finding an appropriate physiotherapist with the expertise to help. Here is a link to a video produced by the Trust showing how physiotherapy can assist thalidomide affected individuals and prevent falls.

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

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 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>Thalidomide Trust. Falls and Balance Problems. May 2019. Available from: [www.thalidomidetrust.org/wp-content/uploads/2016/10/Falls-and-Balance-Problems-Briefing-Paper-FINAL.pdf](http://www.thalidomidetrust.org/wp-content/uploads/2016/10/Falls-and-Balance-Problems-Briefing-Paper-FINAL.pdf)

<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>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>4</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>5</sup>Smithells R, Newman C. Recognition of thalidomide defects. Journal of Medical Genetics. 1992;29(10):716-723.

<sup>6</sup>Part 3: Smoking patterns among adults - NHS Digital [Internet]. NHS Digital. 2020 [cited 27 May 2020]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/statistics-on-smoking/statistics-on-smoking-england-2019/part-3-smoking-patterns-in-adults-copy>

<sup>7</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.

