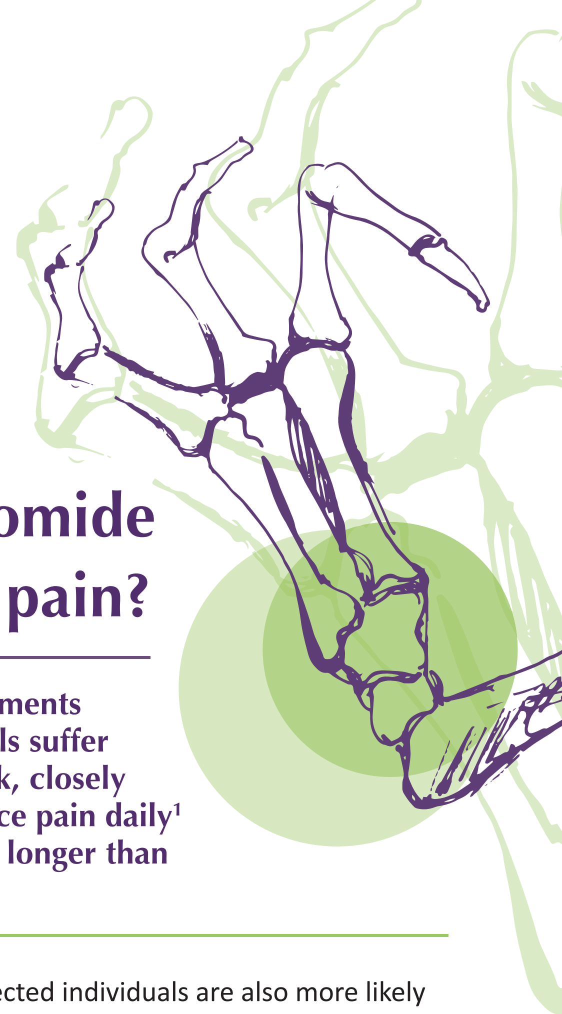
The
# Thalidomide
Trust



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

**Data from the Thalidomide Trust's ongoing Holistic Needs Assessments demonstrates that almost 90% of thalidomide affected individuals suffer from pain, with the commonest sites being the shoulder and back, closely followed by the hip and neck. The vast majority of them experience pain daily[1] and for extended periods. Chronic pain is defined as pain lasting longer than 3 months.**

There are a number of underlying reasons for this including:

- Joints damaged by thalidomide in utero are more prone to arthritis
- Excessive strain is put on other joints which are used to compensate, resulting in early arthritis in these joints
- Functional pain occurs due to abnormal alignment of joints
- Research suggests that compression neuropathies are more common, together with the suggestion of a underlying generalised neuropathy[2]
- Muscle tension and spasm occur due to abnormal postures

## Specific issues to consider

There is a huge overlap with chronic pain and mood disorders[3]. Depression in chronic pain increases the chances of pain treatments not working, increases the intensity of the pain and how long the pain lasts[4,5]. The Thalidomide Trust data shows that their beneficiaries are more likely to suffer from anxiety and depression than the general population. Over 50% of respondents to a Trust survey reported either currently suffering or recently suffering from depression and/or anxiety[6]. The Mental Health Foundation estimates in the UK that 20% of adults in their 50s experience a common mental health problem such as anxiety or depression, the level of poor mental health in thalidomide affected individuals is significantly higher.

Thalidomide affected individuals are also more likely to use alcohol in excess, especially to cope with chronic pain. This can increase the risk of falls, but also increase the risk of side effects or complications from analgesia or anti-inflammatories.

Please refer to the section on 'Psychological Issues'.

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

We would recommend that MSK avenues are explored to ensure steps such as physiotherapy, joint injection and joint replacement have been considered where indicated. Even very dysplastic joints can be amenable to surgery. Please refer to the individual sections in this resource pack for the particular joint involved. In some cases, joint replacement surgery has been life changing.

Please see one example below:

*https://www.thalidomidetrust.org/billys-shoulder-surgery/*

### 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.

Thalidomide affected individuals often have a complex picture of medical issues and psychosocial factors so it's worth considering a referral to a pain clinic for a holistic approach, especially if

the following factors are present:

- Severe pain
- The pain is imposing significant limitations on lifestyle activities or ADLs
- Health is deteriorating and there are other co-morbidities such as diabetes.

## What self management strategies could I recommend?

- Massage therapy can help loosen tight muscles or work on muscle spasms and provide temporary pain relief[7]
- Encouraging gentle exercise and movement. Examples include Tai chi, gardening, 1:1 Pilates or physiotherapy led Pilates. A physiotherapy assessment is a good starting point for anyone with limited movement to show how to exercise safely and correct muscle in-balance or leg length discrepancies
- Some thalidomide affected individuals report benefit from a heat pad, acupuncture and hot tubs
- Weight loss can help improve general mobility
- Pilates and the Alexander technique can help improve posture
- Meditation such as mindfulness can be helpful to reduce depressive symptoms and improve quality of life in those with chronic pain . Apps like "Calm" or "Headspace" can be used for this purpose.
- Vitamin D supplementation should be considered for those with chronic pain[9,10]
- The international medical view, from research and observation, for those with Thalidomide Embryopathy and misaligned joints, is that 'pushing past the pain' as they age should be avoided as this further damages misaligned joints, cause muscle spasm and further puts pressure on normally formed joints used to compensate.
- "Pacing" is a valuable tool in allowing a person with chronic pain to do more. It means breaking down activities into small chunks and taking regular breaks before the pain comes on. The total amount of activity that can be achieved can often be greater with pacing rather than trying to do everything in one go and be at risk of causing a pain flare up-the so-called "Boom and Bust" effect. 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 experience with treating thalidomide affected individuals with 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 the Health Grant (specific funding allocated 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**.


[1]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.

[2]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.

[3]Pereira F, França M, Paiva M, Andrade L, Viana M. Prevalence and clinical profile of chronic pain and its association with mental disorders. Revista de Saúde Pública. 2017;51:96.

[4]Cherkin D, Deyo R, Street J, Barlow W. Predicting Poor Outcomes for Back Pain Seen in Primary Care Using Patients' Own Criteria. Spine. 1996;21(24):2900-2907.

[5]Karp J, Scott J, Houck P, Reynolds C, Kupfer D, Frank E. Pain Predicts Longer Time to Remission During Treatment of Recurrent Depression. The Journal of Clinical Psychiatry. 2005;66(05):591-597.

[6]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.

[7]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.

[8]Hilton L, Hempel S, Ewing B, Apaydin E, Xenakis L, Newberry S et al. Mindfulness Meditation for Chronic Pain: Systematic Review and Meta-analysis. Annals of Behavioral Medicine. 2016;51(2):199-213.

[9]Kragstrup T. Vitamin D supplementation for patients with chronic pain. Scandinavian Journal of Primary Health Care. 2010;29(1):4-5.

[10]Vitamin D for Chronic Pain [Internet]. Practical Pain Management. 2020 [cited 27 May 2020]. Available from: https://www.practicalpainmanagement.com/treatments/nutraceutical/vitamin-d-chronic-pain