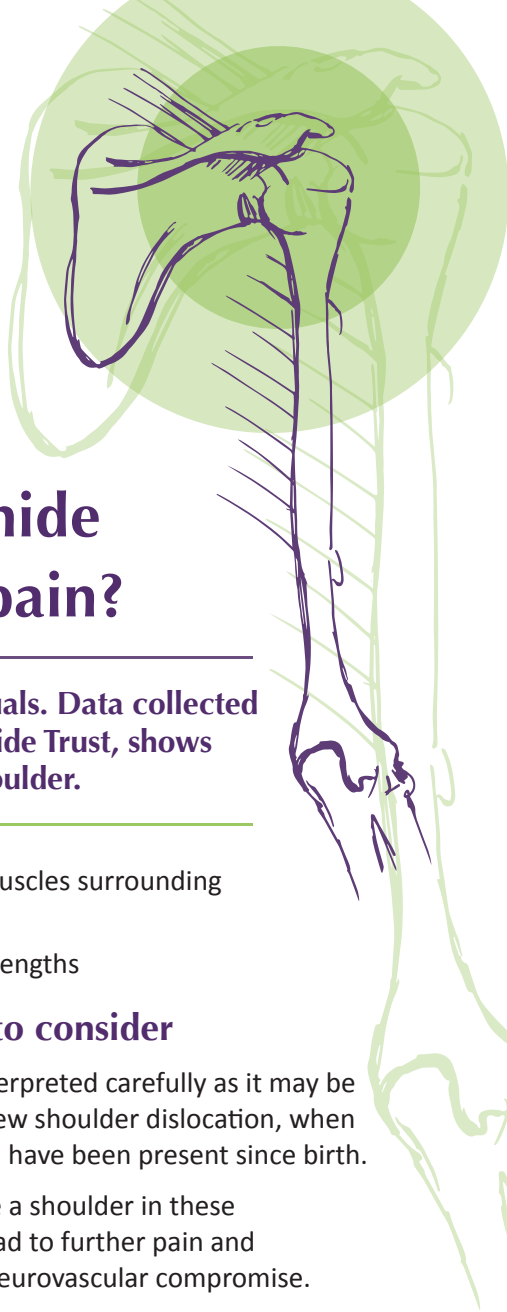
The Thalidomide Trust



Why does my patient with Thalidomide Embryopathy experience shoulder pain?

Shoulder pain is a common complaint in thalidomide affected individuals. Data collected from ongoing Holistic Needs Assessments, performed by the Thalidomide Trust, shows that over half of individuals report pain or loss of movement in the shoulder.

There are a number of underlying reasons for this including:

- Original damage to the shoulders caused by thalidomide[1]
- Overuse of the shoulder and neck to compensate for short reach, by those with short arms, making arthritis more likely[1]
- Reduced muscle strength and joint malalignment are biomechanical risk factors for OA developing[2] which are common in thalidomide affected individuals
- Postural issues such as rounding of the shoulders to compensate for shorter reach can cause neck, back and shoulder pain
- The shoulder joint and the acromioclavicular joint may have to move further if the shoulder is damaged to allow the arm to move.
- Referred pain from the neck which may need separate investigation

Anatomy

Thalidomide affected individuals may display some of the following anatomical features[3,4]:

- A dysplastic shoulder joint which may include an oval rather than a ball-shaped humeral head
- Shoulder dislocation
- Cartilage missing from the acromioclavicular joint
- The clavicle and acromion may be increased in length
- Underdeveloped muscles surrounding the shoulder
- Asymmetrical arm lengths

Specific issues to consider

X-Rays have to be interpreted carefully as it may be assumed there is a new shoulder dislocation, when in fact, this injury will have been present since birth.

Attempting to reduce a shoulder in these circumstances can lead to further pain and disability, including neurovascular compromise.

What can I do for my patient with shoulder 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

X-rays can demonstrate the degree of arthritis and will show the degree of thalidomide damage to the joint but, as stated above, these need to be interpreted with caution.

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 paid for privately.

Steroid injections can be useful to reduce pain whilst physiotherapy is undertaken to strengthen the muscles around the joints. This can be a particularly useful option for thalidomide affected individuals who are reluctant to undergo surgery.

We would recommend an early orthopaedic opinion from a specialist with the expertise to help. Due to the unusual anatomy surgery can be more complex and is best attempted by an experienced Orthopaedic surgeon.

Although an operation is the last resort, surgery should be considered if shoulder pain is affecting quality of life or placing restrictions on activities and affecting independence.

For some of thalidomide affected individuals, shoulder replacement has been life-changing both in pain reduction and maintaining independence – please see one our case studies here https: *https://www.thalidomidetrust.org/billys-shoulder-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[5]
- Some thalidomide affected individuals report benefit from heat pads and hot tubs
- Weight loss can help improve general mobility
- Pilates and the Alexander technique can help improve posture
- 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 shoulder 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**.

[1]Newman R. Shoulder joint replacement for osteoarthrosis in association with thalidomide-induced phocomelia. Clinical Rehabilitation. 1999;13(3):250-252.

[2]Guilak F. Biomechanical factors in osteoarthritis. Best Practice & Research Clinical Rheumatology. 2011;25(6):815-823.

[3]Smithells R, Newman C. Recognition of thalidomide defects. Journal of Medical Genetics. 1992;29(10):716-723.

[4]Mansour S, Baple E, Hall C. A clinical review and introduction of the diagnostic algorithm for thalidomide embryopathy (DATE). Journal of Hand Surgery (European Volume). 2018;44(1):96-108.

[5]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.