



## Why may my patient with Thalidomide Embryopathy be more at risk of mental health problems?

Thalidomide affected individuals are more likely to suffer from mental health problems, like depression and anxiety, than the general population. This was confirmed in a 2015 research study conducted by the Thalidomide Trust which showed that over half of respondents reported either anxiety or depression<sup>1</sup>. Furthermore, the 2018 mood survey carried out by the Thalidomide Trust confirmed that over a third of individuals experienced moderate to severe depression<sup>2</sup>.

This prevalence rate is much higher than the general population. The Mental Health Foundation estimates that 20% of adults in their 50's experience a mental health problem.

There are a number of underlying reasons for this including:

- Many thalidomide affected individuals suffer from chronic pain, making depression and anxiety more common<sup>3</sup>
- Increasing disability and arthritis causing those individuals to stop doing the activities they enjoy
- Traumatic experiences in childhood and how they were subsequently treated, later manifesting as PTSD
- Anxiety about being stared at as a result of their disability and resulting social withdrawal
- Fear and anxiety of increasing loss of independence and reliance on others as they age
- Thalidomide affected individuals are also more likely to drink alcohol to excess

### Specific issues to consider

Be aware that social phobias can be significant. Thalidomide affected individuals can be increasingly socially isolated and have anxiety about going out for

fear of being looked or stared at. This can cause a vicious circle of events with individuals feeling more isolated and more anxious about going out with barriers to accessing appropriate help.

Thalidomide affected individuals may find it difficult to trust medical professionals because of very difficult experiences as children and therefore may find it difficult to attend health appointments.

### What can I do for my patient who is experiencing mental health problems?

#### Investigation

As stated, thalidomide affected individuals may have fears about seeing medical professionals and attend their GP less frequently. Coupled with this they may have social phobias and have become withdrawn from society. It's therefore important to use any contact with a health professional as an opportunity to screen for mental health problems and to enquire sensitively about alcohol use.

#### Referral

Social phobias can be debilitating and this may need referral for psychological therapies in these cases. In addition, please consider the need for referral to local alcohol services and consideration for inpatient or outpatient rehabilitation.

## What self management strategies could I recommend?

- 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
- 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
- Encourage thalidomide affected individuals to think about the activities they most enjoy, for example, gardening and prioritise their activities. Suggest using paid help, family members, or personal assistants to do other more onerous tasks that would otherwise tire them out or cause increased pain, meaning they can still do the activities they enjoy.

## How can the Thalidomide Trust help?

The Thalidomide Trust runs a “Talk Together” programme, which is a confidential peer-support service, providing telephone support from another trained beneficiary to reduce isolation and loneliness. Please contact our Health and Wellbeing team on 01480 47470 for more information.

<https://www.thalidomidetrust.org/health-and-wellbeing/talk-together/>

Individuals can also self-refer to the Thalidomide Trust’s own six session behavioural activation programme, which is delivered by trained thalidomide affected individuals. This is useful for those with mild to moderate anxiety and depression.

The Thalidomide Trust can assist with recommendations of specialists who have the appropriate expertise and who may have experience of treating beneficiaries with mental health problems. In addition, we work with a trained counsellor who acts as a coordinator and can find suitable counsellors in their local area.

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 an individual’s Health Grant (specific funding allocated to each thalidomide affected individual 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>Newbrunner 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>The Thalidomide Trust and University of York. Low Mood Improvement for Thalidomide Survivors - Mood Survey (2018)

<sup>3</sup>Woo A. Depression and Anxiety in Pain. Reviews in Pain. 2010;4(1):8-12.