

The Thalidomide Trust



Additional Issues to Consider

In this section we have included other issues that may be relevant to your thalidomide-affected patient.

Urinary Issues

Is my patient with Thalidomide Embryopathy more likely to have urinary issues?

In a Trust survey, 20% of both female and male thalidomide affected individuals reported bladder or continence problems¹. Urinary symptoms in females may be made worse during the menopause and symptoms can include urgency, frequency and urinary incontinence.

Anatomy

Damage can include absent, horseshoe, ectopic or rotated kidneys, ectopic ureters, vesicoureteric reflux and inert bladders².

Special Considerations

Urinary symptoms can pose significant practical challenges (e.g. having to undress frequently and/or quickly with upper limb damage) and it can be physically and emotionally draining. As a result, some thalidomide affected individuals can restrict their intake of liquids and plan their days to reduce the need for toilet breaks when they leave the house, or stop going out altogether.

Changing incontinence pads and catheters can pose significant challenges to those with short limbs.

What can I do for my patient with urinary issues?

Referral

Referral to a continence or urology service should be considered for all those who are affected by continence issues.

Any condition that can cause or worsen urinary problems such as a UTIs, kidney or bladder stones needs to be dealt with promptly and/or onward referral considered as this can cause a significant reduction in quality of life.

Medication

Consider prescribing HRT in those with symptoms related to the menopause.

Self-management

- Advise on weight loss where appropriate
- Reducing caffeine and alcohol may help with symptoms
- Advice on pelvic-floor exercises

How can the Thalidomide Trust help?

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).

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.**

¹The Thalidomide Trust. (2017) Bladder and Bowel Problems Briefing Paper (Final - May 2017)

²Smithells R, Newman C. Recognition of thalidomide defects. *Journal of Medical Genetics*. 1992;29(10):716-723.