The Thalidomide Trust

Why does my patient with Thalidomide Embryopathy have ear and hearing problems?

38% of thalidomide affected individuals report hearing and ear related issues according to data collected for the Thalidomide Trust[1]. These issues include sensorineural deafness and conductive deafness along with developmental problems of the inner and outer ear structures[2,3].

The picture is further complicated for those with upper limb dysplasia who can have difficulty applying ear treatments or handling hearing aids. Those with microtia and anotia may also have difficulty wearing aids such as hearing appliances and also glasses.

Anatomy

Thalidomide affected individuals may display some of the following anatomical features[2,3]:

- The ear canal can be a blind ended pit or the canals can be narrow/tortuous
- Developmental problems of the outer ear causing microtia or anotia
- Developmental problems of the middle ear causing conduction problems
- Weakness of the facial muscle are also associated with microtia/anotia

Specific issues to consider

Ear examinations can be painful if the ear canal is very narrow so examinations should be done gently.

Narrow ear canals can mean frequent blockages with ear wax.

Some thalidomide affected individuals wear prosthetic ears and can be very self-conscious about removing these.

In those with upper limb dysplasia, it can be difficult without help to apply ear drops and medications such as topical antibiotics.

Given the potential problems with inner ear development, always enquire about balance issues and history of falls (please see the 'Balance and Falls' section).

What can I do for my patient with ear or hearing related issues?

Investigation

Check ear canals and wax. Treating wax can be challenging in those with upper limb deficits who will have difficulties using wax treatments and may need to be referred for micro-suctioning.

Referral

If thalidomide affected individuals are concerned about the cosmetic appearance of their ears, consider referral for bone anchored prosthetic ears or plastic reconstructive surgery for microtia on the NHS. This may become an issue as they age and suffer hair loss, making external ear problems more prominent and this can contribute to depression and anxiety.

Consider the need for lens replacement or laser surgery if wearing glasses is not possible or is challenging for those with microtia/anotia and/or upper limb dysplasia.

How can the Thalidomide Trust help?

The Thalidomide Trust has developed some resources on hearing, hearing tests and hearing aids which you can direct the patient to here: *https://www.thalidomidetrust.org/health-and-wellbeing/health/hearing*

We can assist with writing supporting letters, should the thalidomide affected individual be referred for reconstructive surgery or need lens/laser surgery.

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 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**.

[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]Vargesson N. Thalidomide-induced teratogenesis: History and mechanisms. Birth Defects Research Part C: Embryo Today: Reviews. 2015;105(2):140-156.

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