The Thalidomide Trust



Thalidomide affected individuals are more likely to have risk factors for developing hypertension, for example, they are more likely to smoke than the average person; 25% of thalidomide affected individuals smoke, according to the Thalidomide Trust's data, versus 14% of aged matched people in the general population¹. In addition, their disability creates barriers to both exercise and maintaining a healthy weight² and they are more likely to drink alcohol to excess.

In addition, hypertension is more likely to go undetected in thalidomide affected individuals because:

- many of them are reluctant to seek medical advice and attend GP and nurse appointments for screening
- those with upper limb dysplasia are more likely to have problems with reliable blood pressure measurements being taken.

Anatomy

Thalidomide affected individuals may display the following³:

- Arterial and vascular abnormalities together with abdominal organ malformation that can be present in Thalidomide Embryopathy in addition to the visible damage
- The commonest vascular abnormalities involved renal vessels and supra-aortic arteries but that despite these abnormalities, these organs appear to function normally
- The external pattern of damage does not necessarily correlate with the internal pattern

Specific issues to consider

Thalidomide affected individuals may be reluctant to take medication.

With shortening of the limbs, it can be difficult to both take blood and blood pressure and this can affect diagnosis and monitoring long term⁴.

Although there are a number of current research projects in this area, it is not currently clear how blood pressure in the leg compares to blood pressure in the arm and what the target blood pressure for thalidomide affected individuals should be.

What can I do for my patient?

Investigation

Ensure an accurate BP is taken and the cuff size snugly fits the part of the body chosen – otherwise change the cuff size and/or position on the body. Also ensure the part of the body where the cuff is placed is at the same level as the heart e.g. raise the leg up while the individual reclines and wait 5 minutes. Please see the separate section on "Taking Blood Pressure".

As we don't know what an ideal blood pressure should be if taken in the leg, consider looking for end organ damage by means of ECG to look for LVH, urine tests for ACR and haematuria and examination of the fundi.

Medication

Given the issues with phlebotomy, please consider the ease for future monitoring when prescribing (e.g. ACE inhibitor versus a calcium channel blocker). Individuals may also need additional reassurance as to the continuing need to take medication.

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Referral

If you think a thalidomide affected individual has multiple risk factors and/or a strong family history of cardiac disease and you don't feel confident in assessing their cardiovascular risk, we would recommend referral to a cardiologist for assessment.

What self-management strategies could I recommend?

There are a number of lifestyle changes that can assist in reducing hypertension and it may be helpful to discuss these with a thalidomide affected individual, particularly if they are resistant to taking medication.

How can the Thalidomide Trust help?

The Thalidomide Trust has a number of resources (factsheets and videos) on its website to help with taking of blood and a blood pressure in the leg. The website also contains useful information for thalidomide affected individuals themselves – including a 'How Healthy is your heart?' blog which explains in lay terms the current knowledge regarding Thalidomide Embryopathy and cardiovascular risk.

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 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.



¹Part 3: Smoking patterns among adults - NHS Digital [Internet]. NHS Digital. 2020 [cited 27 May 2020]. Available from:

https://digital.nhs.uk/data-and-information/publications/statistical/statistics-on-smoking/statistics-on-smoking-england-2019/part-3-smoking-patterns-in-adults-copy

²Newbronner 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.

³Weinrich JM, Beyer R, Well L, et al. Assessment of Congenital Vascular and Organ Anomalies in Subjects With Thalidomide Embryopathy Using Non-Contrast Magnetic Resonance Angiography. Circ J. 2018;82(9):2364-2371. doi:10.1253/circj.CJ-18-0414

⁴Beyer, R. Hypertension and sequelae in individuals with thalidomide embryopathy and dysmelia. In Proceedings of Hypertension in Individuals with Thalidomide Embryopathy, October 2016, Hamburg, Germany. Available from:

 $www.research gate.net/publication/329586760_Hypertension_and_Sequelae_in_Individuals_with_Thalidomide_Embryopathy_and_DysmeliaeLines.$