## What does a Lipoedema patient need from you?

Early diagnosis and therefore treatment is paramount in halting progression and improving the prognosis. A diagnosis of Lipoedema, although a relief, can be crushing.

There is no cure and treatment is costly. Many patients have long been diagnosed as obese and it is of little comfort if the focus is again on diet and exercise.

As many patients have experienced fat bias and shaming your approach should be shaped by this experience. As with general population, a focus on good nutrition and gentle exercise is a must.

The prevention of an increase in non-lipoedemic weight and general health and wellbeing will be of great benefit to the Lipoedema patient. It is important that there is a focus on maintenance and halting progression rather than improvement.

There is no standard protocol for treatment but rather a multifaceted, needs-based approach that will focus on improving long term prognosis. A medical approach should include:

- A diagnosis of type and stage.
- Pain management.
- Psychological and emotional support.
- Improve lymphatic flow; compression garments, manual lymphatic drainage,

lymphatic pumps, complete decongestive therapy.

- Healthy eating and the use of a low inflammation diet: Mediterranean, RAD, LCHF, Keto diets with assistance from a nutritionist.
- Low impact exercise that strengthens muscles; whole body vibration, weights, hydrotherapy and water based exercise, walking, rebounding, lymphatic yoga, pilates.
- Assistance investigating appropriate surgical options with suitably qualified and experienced surgeons trained in Lipoedema/ Lymphoedema patient needs.

#### References

- 1. Allen E V, Hines E A, Lipoedema of the legs. A syndrome characterized by fat legs and oedema. Proc Staff. Meet. Mayo Clinic 1940; 15:184 2. Chen, S. G., Hsu, S. D., Chen, T. M., Wang, H. J.
- Painful fat syndrome in a male patient. Br J Plast Surg 2004; 57(3):282-286
- 3. Child, A. H., Gordon, K. D., Sharpe, P., Brice, G., Ostergaard, P., Jeffery, S., Mortimer, P. S. Lipedema: an inherited condition. Am. J. Med. Genet. 152A: 970-976, 2010.
- 4. Schmeller W, Meier-Vollrath I. Erfolgreiche Operative Therapie des Lipodems mittels Liposuktion. Phlebologie 2004; 33: 23 29.
- 5. Vignes S. Lipoedema: A misdiagnosed entity. J Mal Vasc. 2012 Jul;37(4):213-8.
- 5. Wenczl E, Daroczy J. Lipoedema, a barely known disease: diagnosis, associated diseases and therapy. Orv Hetil 2008; 149 (45) 2121-2127.
- 6. Lipedema Description http://www.fatdisorders.org/fat-disorders/lipedema-lipoedema-description
- 7. Lymph and Health: For people with Lymphoedema, Lipoedema and related diseases. Editor: Verein zur Forderung der Lymphoedemtherapie e.V human med AG\_. May 2015



# Lipoedema

#### FOR MEDICAL PROFESSIONALS

Lipoedema Australia advocates for Lipoedema awareness in the public, medical and political arenas.

We are a registered charity that works to find a cause, treatment and cure for Lipoedema. We run a support group, hold regular social gatherings, provide resources, information and emotional support.

Lipoedema Australia believes early diagnosis, appropriate diet, exercise, support and treatment significantly assists in gaining better long-term outcomes for women with Lipoedema. We aim to improve the medical recognition and diagnosis of women with Lipoedema as well as improve access to treatment and foster research in Australia.

www.lipoedemaaustralia.com.au

### Lipoedema

First detailed in 1940<sub>1</sub> Lipoedema is an adipose tissue disorder that affects women, it is rarely seen in men<sub>2</sub>. Women with Lipoedema are rarely indentified by the medical profession and often misdiagnosed and mismanaged. Often diagnosed as Lymphoedema or simple obesity, Lipoedema often goes undiagnosed until the latter stages where a patient develops reduced mobility and comorbidities.

## **Etiology**

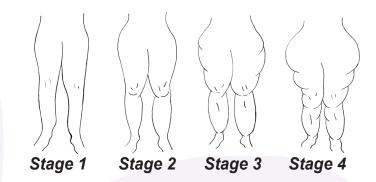
Lipoedema appears to be an inherited disorder where the mode of inheritance appears to be autosomal dominant<sub>3</sub>.

The gene has not yet been identified but is currently being researched in Australia. Metabolic, inflammatory, or hormonal involvement are also evident. It is affected by fluctuating hormones and symptoms increase in severity during puberty, pregnancy and menopause.

Disease onset is usually puberty, but is often not identified and is often associated with chronic venous and lymphatic insufficiency, early degenerative articular disease and obesity. As Lipoedema is not often diagnosed until later stages, co-morbidities and psychological issues are also prevalent and are often what is diagnosed whereby Lipoedema is the primary disorder.

#### Recognising Lipoedema

Symptoms vary, and not all women will experience all symptoms. Rather a combination and increasing severity as the disease progresses.



- Symmetrical accumulation of fatty tissue in legs usually from waist to ankles.
- Feet are not affected with distinctive fat rings around ankles.
- Legs are often hypersensitive to touch and pressure.
- Exercise often causes pain both during and post exercise.
- Lipoedemic fat pads accumulate on upper outer thighs, inner thighs, and above, below and inside the knee – causing abnormal gait and joint pain.
- Lipoedemic fat accumulation in upper arms fat ring around wrists.
- Hypermobility.
- Loss of skin elasticity.
- Non-pitting oedema and negative Stemmer's sign on feet and hands.
- Skin temperature often lowered on arms and legs.
- Restrictive diets have very little effect on lipoedemic fat.

#### Early stages

Fat accumulates predominantly on legs.
Oedema can occur if long periods of time are spent sitting or standing. The upper body remains slim and there can be a 3 or 4 dress size difference between upper and lower body.

### Latter stages

Fat can accumulate on legs, arms also buttocks and torso and may also become fibrotic. Lymphatic insufficiency is often observed with lipo-lymphoedema leading to oedema in feet and hands. Cellulitis is common and deterioration of mobility is often greatly reduced leading to immobility and co-morbidities.

Depression and eating disorders are very common in Lipoedema patients. This is due to diets being ineffective and exercise producing little results. Misdiagnosis of obesity and inability to make change leads to depressive episodes and poor self esteem. A German study reported that up to 74% of Lipoedema patients develop eating disorders and 90% reported moderate to severe psychological pain from having 'legs that ruined their lives'?

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