Dear Colleague,

Thank you for the opportunity to introduce to you a fat disorder called **Lipoedema** (sp., **lipedema**). It was once believed to be a rare condition, however recent studies show this condition affects 11% of all women. **Lipoedema** is NOT obesity. It is a subcutaneous fat disorder that is not due to excess caloric intake or inadequate exercise. Instead, it is the result of malfunctioning adipocytes, "leaky" lymphatics and increased angiogenesis. **Lipoedema** appears to be inherited as an autosomal dominant pattern, expressed in women with male sparing, and most often associated with a hormonal change in those afflicted. It is often a painful disorder, hence the name "painful fat disorder", and the sooner it is recognized and treated, the more favorable the patient response in preventing progression to Stage 4 ***lipo-lymphoedema*** – a disabling condition.

Your patient is sharing this letter with you as she believes she may have **lipoedema**. She has highlighted the following to assist in diagnosing her with **lipoedema**:

DIAGNOSTIC CRITERIA FOR LIPOEDEMA:

- Female (**lipoedema** occurs almost exclusively in women)
- Both legs, hips and or buttocks are affected with sparing of the feet and are similar on both sides of the body (bilateral, symmetrical manifestation with minimal involvement of the feet – will have a "cuff" or "cut off" sign at the ankle)
- Minimal pitting edema
- Negative Kaposi–Stemmer sign initially (though initially negative, it manifests as the patient progresses to Stage 4 ***lipo-lymphoedema***).
- Pain and tenderness over areas of fatty tissue, especially with pressure
- Easy bruising over areas of fatty tissue without significant injury
- No resolution with elevation or weight loss
- Arms affected 30% of the time
- Coolness over the skin of affected areas (hypothermia of the skin)
- Swelling worsens with orthostasis in summer
- **Unaffected by caloric restriction**
- Telangiectasias

Lipoedema does not respond to typical caloric restriction or exercise, although a healthy diet and activity are important to prevent the development of obesity and immobility, both of which can worsen **lipoedema**. The treatment of **lipoedema** benefits from the involvement of a multi-disciplinary team including social/psychological support, manual lymphatic drainage, compression garments, proper diet and physical activity, all of which are also recommended for ***lymph***oedema. No medications or supplements are currently approved for the treatment of **lipoedema**, although some are used (successfully) in an off-label manner. Tumescent liposuction may help alleviate pain and improve mobility in these patients for a period of time. Online resources include: www.lipedemaproject.com, www.lipoedema.co.uk.

We are currently working with the NZ Ministry of Health to include the updated ICD-10 Codes, used elsewhere in the world, to include lipoedema (the closest code at this time is E88.2 for Adiposis Dolorosa/Dercum's Disease).

Thank you for your consideration of this diagnosis for your patient. If appropriate, please consider referring her for further assessment with a local lymphoedema team for compression garments and manual lymphatic drainage if a consultant familiar with lipoedema management if not available in your region. Please let us know if we can be of assistance.

Kind regards,

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