

**Hardy, D., and Williams, A. 2017. Best Practice Guidelines for the Management of Lipoedema. British Journal of Community Nursing, Chronic Oedema Supplement, October S44, 46, 48**

The Best Practice Guidelines for the management of lipoedema were published earlier this year by Wounds UK, following a collaborative development and peer review process. This paper provides an overview of the development process, and a summary of key messages from the guidelines.

The idea of establishing UK-specific guidelines was first discussed by a group of clinicians in 2015. Supported by Wounds UK, industry and third sector partners, an Expert Working Group was brought together in September 2016. This initial meeting was the start of a creative process, and provided a framework for the subsequent development of the evidence-based guidelines.

The Expert Working Group was co-chaired by two lymphology nurse consultants, with writing and editorial support from Wounds UK. The group included three women living with lipoedema, specialist nurses and physiotherapists, a consultant in dermatology and lymphovascular medicine, and a dietician. The guidelines were reviewed by an expert panel.

The group recognised the three significant challenges relating to lipoedema treatment and support in the UK:

- The poor awareness of the condition among health professionals
- The psychosocial, emotional distress and co-morbidities experienced by women with lipoedema;
- The geographical variations in clinic availability, with limited access to services in many areas.

The guideline document aims to be comprehensive, realistic, and accessible to people affected by lipoedema, health professionals, and those who commission services. Understanding of lipoedema pathophysiology and research evidence relating to management of lipoedema is continually developing. The guidelines are scheduled to be reviewed and updated within three years.

The key messages within the nine sections of the guidelines are summarised below:

### *Section 1: Epidemiology and pathophysiology of lipoedema*

Lipoedema predominately affects women, and is a chronic fat and connective tissue disorder. It typically affects the thighs, buttocks, lower legs and/or arms (with sparing

of the feet/hands), leading to tissue enlargement, swelling and pain that may impair mobility, daily living activities, and psychosocial wellbeing. The prevalence of lipoedema in the UK is estimated to be 1 in 72,000 (Child et al 2010) although this may be underestimated, as women are often misdiagnosed with obesity or lymphoedema. Precise mechanisms responsible for the development of lipoedema are unknown, but it is likely that multiple factors are involved (Okhovat & Alavi 2014).

Changes include increased numbers and/or size of fat cells, reduced elasticity of the skin and connective tissue (Jagtman et al 1984; Herbst 2012), inflammatory processes, (Suga et al 2009), and growth of new capillaries in the fat tissue, associated with bruising (Fife et al 2010). Lipoedema may be accompanied by increased interstitial fluid, which overloads the lymphatic system, leading to a secondary lymphoedema, often referred to as lipo-lymphoedema (Cornely 2006). There is some evidence of a genetic predisposition to lipoedema, although genetic variants involved have not been fully identified (Child et al 2010).

### *Section 2: Diagnosis and assessment*

In the absence of specific diagnostic markers or investigations for Lipoedema, diagnosis is based on clinical examination and history. Making a diagnosis can be challenging, particularly in the early stages, or if the person has co-existing obesity. Tissue enlargement is usually bilateral and symmetrical, affecting legs, thighs, hips and buttocks, with sparing of the feet. The guidelines identify areas for discussion in the assessment including: age at onset; family history; areas affected; effect of dieting; pain; bruising, skin texture and temperature; impact on daily living activities and gait; shape disproportion, clothing; and other medical history. Additionally, the person's understanding of the disease and expectations of treatment outcomes should be explored.

Table 1. Summary of the staging system for lipoedema in the guidelines
Stage 1: Skin appears smooth; thickened subcutaneous tissue may contain small nodules
Stage 2: Skin has an irregular texture that may resemble 'orange peel'; subcutaneous nodules occur

Stage 3: More prominent indurations of the tissues; deformed fat deposits particularly around the thighs and knees

Stage 4: Lipoedema with secondary lymphoedema (lipo-lymphoedema)

### *Section 3: Principles of management*

Individuals with lipoedema often feel vulnerable and sensitive after an often protracted journey to diagnosis. A multidisciplinary approach is recommended, working in partnership with patients, providing support and encouragement, and focussing on three key principles of lipoedema management:

- Facilitation and enhancement of the patient's ability to self-care
- Optimisation of health and prevention of progression
- Management of symptoms.

The main components of lipoedema management are psychosocial support, healthy eating and weight management, physical activity and improving mobility, skin care and protection, compression therapy and management of symptoms such as pain. Early diagnosis, intervention and initiation of self-care are likely to produce health and economic benefits. Lymphoedema services may provide specific expertise in differentiating the condition, use of compression therapy, and specialist treatment advice; but such intervention is dependent on the clinic referral criteria. Third Sector organisations such as Lipoedema UK and Talk Lipoedema are important sources of peer support and self-management advice.

### *Section 4: Psychological support and self-care*

Psychological adjustment to lipoedema may have a major impact on outcomes, and mental health issues such as depression, anxiety or psychological distress can compromise the ability to self-manage (Dekker & de Groot 2016). The guidelines identify potential barriers to self-care in patients with lipoedema such as lack of knowledge and skills, low self-esteem, poor relationships with professionals, and financial restrictions. Many people with lipoedema adjust well to living with lipoedema, while some may benefit from interventions such as counselling, cognitive behaviour

therapy or mindfulness. Access to such support can however be varied and limited within the NHS.

### *Section 5: Healthy eating and weight management*

The guidelines provide a critical overview of dietary and physical activity approaches. Nutrition has an important role in weight management, promoting a sense of control, and reducing the risk of obesity-related conditions. The Lipoedema UK Big Survey 2014 reported that 98% of participants had tried to lose weight (Fetzer and Fetzer 2016). However weight loss programmes have little or no effect on lipoedema fat. People with lipoedema are likely to have tried a variety of diets, and may have a complex relationship with food.

Physical activity should also be encouraged in people with lipoedema, and is useful in weight management, improving mobility (Fetzer & Wise 2015), and enhancing psychological wellbeing. Exercise should be individualised, and may include walking, water-based activities or group classes. However, it should not exacerbate pain, joint strain or bruising. People with lipoedema who have severely impaired mobility, abnormal gait, pain and joint problems should seek physiotherapy advice.

### *Section 6: Skin care and protection*

The guidelines highlight the importance of skin care and prevention of cellulitis, a particular risk for people who have secondary lymphoedema.

### *Section 7: Compression therapy*

In lipoedema, compression has three main purposes:

1. To reduce discomfort, aching and pain, by providing containment and supporting the tissues.
2. To streamline uneven, distorted limb shape and improve movement.
3. To reduce oedema in lipo-lymphoedema by reducing interstitial fluid formation and encouraging venous and lymphatic return.

Although it will not reverse adipose tissue enlargement, compression therapy may prevent lipoedema worsening, decreasing the risk of progression to secondary lymphoedema. Careful assessment is required to determine what type of compression

therapy is indicated. Personalised selection of compression therapy must take into account the location, extent and severity of the lipoedema, lifestyle, and presence of symptoms such as pain or oedema.

A creative and flexible approach is required, for example: starting with low levels of compression and building gradually to improve tolerance; use of flat-knit, footless garments; or combining different types of garments such as a Bermuda-style garment with adjustable wraps for the lower leg. Multi-layer bandaging may be indicated to manage oedema in a patient with lipo-lymphoedema. Intermittent pneumatic compression pumps may be useful in managing symptoms such as pain and oedema.

### *Section 8: Other non-surgical approaches*

The guidelines provide an overview of additional treatment options including manual lymphatic drainage, kinesiology taping, Deep Oscillation therapy and self-lymphatic drainage or dry skin brushing. However the evidence is limited and more research is required.

### *Section 9: Surgical management*

Surgical options, appropriate for some patients with lipoedema, include liposuction to treat tissue enlargement, and bariatric surgery to treat obesity. Although it is not a cure, there is some evidence that liposuction can lead to improvements in pain, bruising, oedema mobility and quality of life (Schmeller et al 2012; Baumgartner et al 2016). Liposuction must be performed by a surgeon who is appropriately qualified and works as part of a multi-disciplinary team. Adjuvant compression therapy is usually essential to achieve an effective outcome from surgery. Pre-operative counselling can ensure that the person has realistic expectations of what can be achieved. Due to lack of NHS provision, some individuals seek surgery privately in the UK or abroad, and are advised to fully research their clinic of choice. Readers are also directed to the National Institute for Health and Care Excellence (NICE) guidelines on criteria for considering bariatric surgery (NICE 2014).

### *Conclusions*

People living with lipoedema can feel misunderstood and rejected by health care services as their condition is often misdiagnosed as obesity or lymphoedema. The guideline document aims to be comprehensive, realistic and accessible to people with

lipoedema, health professionals, and commissioners of services. Challenges relating to lipoedema treatment and support in the UK include: poor awareness of the condition among health professionals, and limited access to services. A multidisciplinary approach is recommended, focussing on facilitation and enhancement of the person's ability to self-care, optimisation of health, prevention of disease progression and management of symptoms.

Psychological adjustment to lipoedema may have a major impact on outcomes, and mental health issues such as depression, anxiety or psychological distress can compromise the ability to self-manage. The guidelines are a first step to achieving better care, treatment and support for people with lipoedema who often feel ignored and rejected by healthcare services. They will enhance the recognition of the condition by healthcare professionals and help to improve access to high quality services by promoting collaboration between people with lipoedema, practitioners, industry and the third sector.

The Best Practice Guidelines are available for download from: [www.wounds-uk.com](http://www.wounds-uk.com)

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