Summary of guidance

The CCG will fund conservative (non-surgical) treatments for lipoedema in line with the Lipoedema Patient Pathway developed by the Expert Working Group, through specialised lymphoedema community services. These include compression therapy, manual lymphatic drainage and other conservative treatments deemed appropriate.

Liposuction for lipoedema is not routinely available. However it may be available in exceptional circumstances in patients with the following eligibility criteria:

- Those with severe symptoms that acutely affect day to day functions.
- They are documented to have fully complied with conservative treatments for over 12 months.
- They have achieved required weight loss (where required)
- The patient continues to experience severe symptoms.

Decision on who is eligible will be decided on an individual basis and will be managed through the IFR process.

Note: Lipoedema is a different condition to lymphoedema. Although it is often misdiagnosed as lymphoedema and there are some similarities in treatment and similar specialists treat both conditions. However they are distinct conditions and differences are noted clearly in table 2 below.

Lipoedema has been classified according to both distribution of the adipose tissue and enlargement and the shape of the enlargement. However, these classifications are of limited clinical use because neither indicates severity or disease progression, and neither guides treatment.

There is no information currently available on cost effectiveness of surgical interventions.

Summary

- Lipoedema is a chronic and progressive disease characterised by bilateral symmetric enlargement of the legs as a result of abnormal deposition of subcutaneous fat and orthostatic edema.
- It is an underdiagnosed condition and almost exclusively affects women.
- Hormonal and genetic factors are likely to contribute to the adipose tissue enlargement characteristic of lipoedema however the causes are not fully understood.
- Lipoedema is often misdiagnosed as lymphoedema or obesity, however there are significant differences between them.
- Assessment of a patient with lipoedema needs to incorporate a wide range of factors, including physical and psychosocial effects.
Management of lipoedema requires a multidisciplinary approach, including specialised compression therapists, nutrition, psychosocial support and skin care and pain management. ii

Surgical treatments such as liposuction are available, and may be appropriate for some patients, although no treatments are curative ii. There have been a small number of trials showing positive effects following TLA liposuction for patients with lipoedema.

The Expert Working Group has developed a patient pathway and it is recommended that this could be utilised locally for treatment of patients with lipoedema II.

An online e-learning course is available developed by Lipoedema UK and RCGP. It can be accessed at www.elearning.rcgp.org.uk/lipoedema II

Introduction
Lipoedema was first described in the 1940’s in the USA IV it is a chronic and progressive disease V characterised by bilateral symmetric enlargement of the legs as a result of abnormal deposition of subcutaneous fat and orthostatic edema I. It results in pain, tenderness, sensitivity to pressure and easy bruising I. It is almost exclusively found in women I VI and often starts after puberty and is a lifelong condition I. Although it is sometimes associated with obesity, this is not always the case and the excess fat cannot be reduced by either exercise or dieting I.

Lipoedema is an often undiagnosed or can be misdiagnosed as lymphedema or obesity, but there are significant differences in the conditions VI Many physicians in general practice are unaware of lipoedema and patients can be dismissed as obese and told to lose weight however reducing calorie intake has no effect on lipoedema. Although awareness is increasing lipoedema is still an under-diagnosed condition V.

An Expert Working Group (EWG) was developed in 2015 (for members see appendix I) to explore best practice for diagnosis and management of lipoedema based on evidence where available and expert opinion where evidence was lacking. The results were published in March 2017 and from the basis for this report I.

Prevalence
Relatively little epidemiological research has been carried out on lipoedema so these are estimates. The minimum prevalence is thought to be 1 in 72,000 IV whereas in Germany is has been estimated as high as 1 in 9 II.

Cause
The precise mechanisms for development of lipoedema are unknown but it is likely that both hormonal and genetic factors are involved II.

Diagnosis of Lipoedema
There are no known blood or urine biomarkers or any diagnostics tests; therefore diagnosis is made on clinical grounds based on patient history and examination. The condition is poorly recognised which often leads to delays in correct diagnosis. Table 1 below identifies the clinical signs of lipoedema II.
Lipoedema is often misdiagnosed as it is mistaken for other conditions that also cause subcutaneous tissue enlargement/swelling or fat deposition. Most frequently these are obesity and lymphoedema. However there are significant differences between these conditions and lipoedema. See table 2 below highlighting the differences between these conditions.
Classification and Staging

Lipoedema can be classified according to either the distribution of the adipose tissue or the shape of the enlargement. However neither of these classifications indicates severity of disease progression or guide treatment.ii Best Practice guidelines recommend using a holistic assessment of people with lipoedema as can be seen in table 3 below.

Table 3: Holistic Assessment on a person with lipoedema

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Lipoedema</th>
<th>Lymphoedema</th>
<th>Obesity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Almost exclusively female</td>
<td>Male or female</td>
<td>Male or female</td>
</tr>
<tr>
<td>Age at onset</td>
<td>Usually 10-30 years</td>
<td>Childhood (mainly primary); adult (primary or secondary)</td>
<td>Childhood onwards</td>
</tr>
<tr>
<td>Family history</td>
<td>Common</td>
<td>Only (or primary lymphoedema)</td>
<td>Very common</td>
</tr>
<tr>
<td>Areas affected</td>
<td>Bilateral</td>
<td>May be unilateral or bilateral depending on cause</td>
<td>All parts of the body</td>
</tr>
<tr>
<td></td>
<td>Usually symmetrical</td>
<td></td>
<td>Usually symmetrical</td>
</tr>
<tr>
<td></td>
<td>Most frequently affects legs, hips and buttocks; may affect arms</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Feet hands spared</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Effect of dieting on condition</td>
<td>Weight loss will be disproportionately less from lipoedema sites</td>
<td>Proportionate loss from trunk and affected limbs</td>
<td>Weight reduction with uniform loss of subcutaneous fat</td>
</tr>
<tr>
<td>Effect of limb elevation</td>
<td>Absent or minimal</td>
<td>Initially effective in reducing swelling may become less effective as the disease progresses</td>
<td>None</td>
</tr>
<tr>
<td>Pitting oedema (Box 5, page 8)</td>
<td>Absent or minor in the early stages of the disease</td>
<td>Usually present but pitting may cease as the disease progresses and tissues fibrose</td>
<td>No</td>
</tr>
<tr>
<td>Bruises easily</td>
<td>Yes</td>
<td>Not usually</td>
<td>No</td>
</tr>
<tr>
<td>Pain/discomfort in affected areas</td>
<td>Often</td>
<td>May be uncomfortable</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Hyperesthesia to touch in affected areas</td>
<td>No hyperesthesia to touch</td>
<td>No</td>
</tr>
<tr>
<td>Tenderness of affected areas</td>
<td>Often</td>
<td>Unusual</td>
<td>No</td>
</tr>
<tr>
<td>Skin consistency</td>
<td>Normal or softer/looser</td>
<td>Thickened and firmer</td>
<td>Normal</td>
</tr>
<tr>
<td>History of cellulitis</td>
<td>Unusual (unless lipoedema is present)</td>
<td>Often</td>
<td>Unusual</td>
</tr>
<tr>
<td>Stemmer's sign (Box 4, page 7)</td>
<td>Usually negative (unless secondary lymphoedema is present)</td>
<td>Usually positive</td>
<td>Usually negative</td>
</tr>
</tbody>
</table>

Management of lipoedema

As lipoedema is a long term condition with wide ranging impacts on health and psychosocial wellbeing there is a need for an interdisciplinary approach to management. The expert working group concluded that specialised lymphaedema services are best placed (where available) to manage patients with lipoedema, due to expertise in differentiating between these conditions and their experience of delivering compression therapy.

Principles of Lipoedema Therapy

1. Facilitating and enhancing the patients ability to self-care and cope with the physical and psychosocial impact of the condition
2. Managing symptoms
3. Optimising health and preventing disease progression

The main components of lipoedema management are:

1. Psychosocial support and education
2. Healthy eating and weight management
3. Physical activity and improving mobility
4. Skin car and protection
5. Compression therapy
6. Pain management

There is currently no evidence that early intervention improves prognosis in lipoedema, the EWG consider that early diagnosis and treatment and self-care would produce the greatest health and economic benefit. As yet no formal health economic analysis has been undertaken.ii

**Surgical management of lipoedema**

Until the early 2000’s there was no alternative to the conservative treatments as liposuction was determined to have too many side effectsv however development of tumescent liposuction analgesia (TLA) around 2002 resulted in provision of an alternative therapy.i, v The TLA process involves large amounts of fluid infiltrating the subcutaneous tissue with a blunt vibrating microcannula. Between 10 and 20 litres of fluid can be removed and therefore reduces the presences of subcutaneous fatty tissue1 (see footnote1 for further details of TLA process)

Many studies have shown that when delivered appropriately TLA has a range of positive effects on patients, including reduction in pain, sensitivity, bruising tenderness and swelling and increased mobility and quality of life of patients.vii

**Issues with TLA liposuction**

- There is no NICE guidance available regarding liposuction for lipoedema, although IPG588 ‘Liposuction for chronic lymphoedema’ does make some recommendations on its use.viii
- No cost effectiveness studies have been published on the use of TLA liposuction for lipoedema, however some studies have suggested that the reduction in need for conservative treatments may show a cost saving over the long termix.
- Studies have shown that in many cases patients require more than one surgery, i and in some cases up to four surgeries are required to effectively treat their lipoedema. This needs to be taken into account with any requests for treatments.
- TLA results in reduction in many of the effects of lipoedema, however individuals may continue to require some conservative treatments.x

**Contraindications and conditions for surgery**

- Patients need to fully understand of possible side effects2, 3, 5, xi

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1 Tumescent local anaesthesia (TLA) is a form of regional anaesthesia in which the subcutis is infiltrated with large volumes of a diluted anaesthetic. The main constituent of the TLA solution is physiological saline, to which a local anaesthetic (usually lidocaine or a combination of lidocaine and prilocaine) is added. If prilocaine is used, the risk of methaemoglobin formation needs to be considered. The TLA solution also contains adrenaline, sodium bicarbonate and triaminocline. The handling of TLA in liposuction requires some familiarisation on the part of beginners. Since by the end of infiltration, the large amounts of fluid have made the tissue taut and elastic, its contours are eliminated. In addition, it is difficult to evaluate the result because of remaining postoperative fluid. Nevertheless, with adequate experience the advantages of this technique far outweigh the disadvantages1
• Patients may require >1 surgery, and up to 4 surgeries to reach an acceptable level of improvement\(^1\)
• Experience of the surgeon performing the surgery, considerable experience is required \(^4\ \text{xii}\)
• All studies note that conservative treatment should be tried in the first instance. \(^\text{iii, iv, vi & x}\)
• There is no correlation between amount of fat removed and extent of improvements, also there is no evidence of a link between age of patient, duration of lipoedema, or duration of conservative therapy on success of the procedure.\(^\text{ix}\)
• Obesity must be controlled beforehand \(^\text{v, (taking the lipoedema into account)}\)
• Patients need to maintain a healthy lifestyle post-operatively
• Patients may require continuation of conservative therapy \(^\text{ix}\)
• Side effects are more likely when obese, using hormonal contraception, smoking, and history of clotting disorders.\(^\text{iii}\)
• Patients with heart failure, bradycardia, AV block arrhythmia, truncal obesity and dysmorphophobia are unsuitable for treatment.\(^\text{iii}\)
• Other factors affecting side effects include the quality of compression treatment and post-operative lymphatic drainage\(^\text{iii}\)

*Patient pathway developed by Expert Working Group*\(^\text{ii}\)

The EWG have developed this patient pathway to support clinicians in diagnosis, assessment and management of lipoedema.
Patient presents with blunted tissue enlargement

**General practitioner** suspects or diagnoses lipoedema
- Initial routine blood tests, e.g. urea and electrolyte, thyroid function tests, oestrogen, proteins, glucose, brain natriuretic peptide (BNP)
- Referral to lipoedema/lymphoedema service/clinic

**Lipoedema/lymphoedema service/clinic**
- Confirmation of diagnosis and further investigations if required
- Initial assessment, including:
  - Site, extent and shape/disproportion of tissue enlargement; weight
  - Presence of oedema/test for Stemmer's sign
  - Assessment for chronic venous insufficiency (CVI)
  - Pain and psychological assessments
  - Assessment of functioning and mobility

**Referral as appropriate, e.g.**
- Pain management
- Dietitian
- Physiotherapy
- Occupational therapy
- Counselling/psychological therapy
- Leg ulcer management
- Dermatology

**Education**
- Healthy eating/weight management (diet)
- Physical activity

**Skin care**
- Treatment of concomitant conditions
- Support with and encouragement of self management

**No oedema**

**Oedema (lipolymphoedema)**

**Mild to moderate enlargement**
- No deep skin folds or fat lobes

**Moderate to severe enlargement**
- Fat lobes and deep skin folds

- Class 1 ready-to-wear circular knits or sports skins/compression clothing or burnums garments
- If pain or tissue tenderness make donning the garment difficult or hinders the patient from tolerating it, adjustable compression wraps may provide the patient with additional support
- Consider MLD

- Class 1 or 2 made-to-measure flat knit garments
- Adjustable compression wraps if patient has difficulty applying flat knit garments or is hindered because of pain or tissue tenderness
- Consider IPC

- Minor oedema
  - Class 1 or 2 ready-to-wear circular knits/made-to-measure or adjustable compression wrap if problems with toleration or donning/stocking
  - More extensive oedema and/or severe pain:
    - Consider course of multi-layer bandaging to reduce oedema to level where compression garments or wraps are appropriate
    - Consider IPC
    - Consider kinesiology taping

**Moderate to severe enlargement**
- Fat lobes and deep skin folds

- Multi-layer bandaging until oedema, and pain if present, is sufficiently reduced to a level where Class 1 or 2 made-to-measure flat knit garments or adjustable compression wraps are appropriate and tolerable
  - Consider MLD
  - Consider IPC
  - Consider kinesiology taping

Monitor outcomes regularly, aiming for outcomes as agreed with the patient which may include:
- Reduced pain
- Reduced oedema
- Improved mobility and functioning
- Enhanced self management

For patients with moderate to severe lipoedema, consider referral for liposuction after 6-12 months of non-surgical management

N.B. The algorithm is a guide - the compression and treatment regimen for a particular patient should be individualised to take account of all of their needs
IPC: intermittent pneumatic compression; MLD: manual lymphatic drainage
Appendix I Membership of Expert Working Group and Review Panel.

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Melanie Thomas MBE, National Clinical Lead for Lymphoedema, NHS Wales and the Lymphoedema Network Wales
## Appendix II: Evidence of liposuction for lipoedema

<table>
<thead>
<tr>
<th>Authors</th>
<th>Sample size</th>
<th>Changes in symptoms</th>
<th>Number of surgeries required</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schmeller and Meier-Vollrath (2006)&lt;sup&gt;v&lt;/sup&gt;</td>
<td>21</td>
<td></td>
<td>1=15 (54%) 2=8 (29%) 3=2 (7%) 4=3 (11%)</td>
<td>Minor hematomas and post-operative swelling for a few days.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptom</td>
<td>No. Before surgery</td>
<td>After surgery</td>
</tr>
<tr>
<td>Spontaneous pain</td>
<td>18</td>
<td>18</td>
<td>2 (11%)</td>
<td>10 (56%)</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>21</td>
<td>21</td>
<td>0(0%)</td>
<td>13 (62%)</td>
</tr>
<tr>
<td>Swelling</td>
<td>21</td>
<td>21</td>
<td>0 (0%)</td>
<td>17 (81%)</td>
</tr>
<tr>
<td>Bruising</td>
<td>20</td>
<td>20</td>
<td>2 (10%)</td>
<td>13 (65%)</td>
</tr>
<tr>
<td>Quality of life</td>
<td>21</td>
<td>21</td>
<td>0 (0%)</td>
<td>21 (100%)</td>
</tr>
<tr>
<td>Rapprich et al 85 (2015)&lt;sup&gt;x&lt;/sup&gt;</td>
<td>85</td>
<td>symptom</td>
<td>Change VAS (1-10)</td>
<td>P value</td>
</tr>
<tr>
<td>Pain</td>
<td>6.5-2.12</td>
<td>(p&lt;0.001)</td>
<td></td>
<td>1 = 16.9%</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>6.5-2.4</td>
<td>(p&lt;0.001)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bruising</td>
<td>8.1-4.3</td>
<td>(p&lt;0.001)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swelling</td>
<td>6.3-3.2</td>
<td>(p&lt;0.001)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking</td>
<td>4.1-1.2</td>
<td>(p&lt;0.001)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of life</td>
<td>8.5 – 3.3</td>
<td>(p&lt;0.001)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chen et al (2003)&lt;sup&gt;iv&lt;/sup&gt;</td>
<td>1</td>
<td>Improvement was seen cosmetically and symptomatically reduction in calf circumference from 57cm to 48cm 39-34 one calf and 41 to35 for the other</td>
<td>1 seroma</td>
<td></td>
</tr>
<tr>
<td>Baumgartner, et al (2015)&lt;sup&gt;iii&lt;/sup&gt;</td>
<td>85</td>
<td>Patients followed up after 4 and 8 years post-operatively. Results from 8 years found that all improvements from 4 years had persisted.</td>
<td>N/A</td>
<td>U/K</td>
</tr>
<tr>
<td>Rapprich, Dingler, Podda (2011)&lt;sup&gt;x&lt;/sup&gt;</td>
<td>25</td>
<td>Leg volume reduced by 6.9% Pain from 7.2-2.1 (p&lt;0.001) Quality of life 8.7-3.6 (p&lt;0.001)</td>
<td>U/K</td>
<td>U/K</td>
</tr>
</tbody>
</table>
References

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