

Living with lipoedema: reviewing different self-management techniques

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When patients receive a diagnosis of lipoedema, most would feel a sense of relief to know they have a medical condition and that they are not 'just fat' and it is not 'their fault'. There is often a great deal of frustration to discover that, as yet, there remains no proven cure. However, much can be done to help improve symptoms and prevent progression. Significant improvements can be achieved by following a sensible, healthy eating programme designed to lose any excess weight and to prevent further weight gain (Langendoen et al, 2009). Following an appropriate exercise schedule to build muscle tone and wearing appropriate, graded compression garments to support the tissues and reduce oedema (fluid build up) will help maintain an active lifestyle (Langendoen et al, 2009; Lipoedema UK, 2013; Wise, 2013). Other techniques, such as self-lymphatic drainage and counseling, can also help with relief and provide support.

What is lipoedema?

Lipoedema is chronic adipose tissue, or fat, disorder (Todd, 2010; Lipoedema UK, 2013). It is likely that there is an underlying genetic predisposition, as a number of women have a family history of the condition (Mortimer and Gordon, 2015). This condition is estimated to affect up to 11% of the female population (Földi and Földi, 2006; Fonder et al, 2007), and the condition is not thought to affect men (Langendoen et al, 2009).

Frequently misdiagnosed as obesity and/or lymphoedema (Todd, 2010), excessive (abnormal) and symmetrical fat distribution occurs predominantly from the waist down to the ankles, resulting in the lower limbs becoming disproportionately larger than the upper torso. This is an important characteristic of lipoedema, whereas in generalised obesity, excessive fat distribution occurs all over the body. As the condition develops, areas affected by lipoedema can be tender, and bruise easily. Over time, the tissues become loose and floppy and develop a 'mattressing' effect with distinctive fat pads above and below the knees. Many patients also suffer from knee pain. The differences between lipoedema, lymphoedema, and obesity are outlined in *Table 1*.

Despite being first recognised by the medical community 64 years ago (Wold et al, 1951), lipoedema is rarely

recognised in primary care and is therefore underdiagnosed (Goodliffe et al, 2013; Lipoedema UK, 2013). Research by the charity Lipoedema UK (2013) found that only 5% of GPs recognised the condition to enable diagnosis. Since the launch of a Royal College of General Practitioners (RCGP) Lipoedema e-learning course in 2014, this trend is changing. Endorsed by the Royal College of Nursing (RCN), the course can be taken as part of ongoing professional development. The course is free and is available to all allied health professionals. This is a vital tool, but raising awareness of the condition in primary care is still a key issue.

Awareness of lipoedema remains poor among medical professionals (Lipoedema UK, 2013), and there has been relatively little clinical research focused on the condition. The majority of patients are diagnosed and treated by specialists working in lymphology. Even when women receive a diagnosis, it can be difficult for them to access information on the treatments and lifestyle behaviors that can be of benefit. These range from self-management techniques, such as maintaining a healthy weight and the use of graduated compression garments, to specialist interventions, such as manual lymphatic drainage and liposuction, although the latter is rarely available on the NHS.

The first step for patients is to try and access lipoedema services at lymphoedema clinics. Lymphoedema nurses

ABSTRACT

At present, there is no proven cure for lipoedema. Nevertheless, much can be done to help improve symptoms and prevent progression. Many of these improvements can be achieved by patients using self-management techniques. This article describes the range of self-management techniques that community nurses can discuss with patients, including healthy eating, low-impact exercise, compression garments, self-lymphatic drainage, and counselling.

KEY WORDS

♦ Lipoedema ♦ obesity ♦ self-management ♦ counseling
♦ compression garments

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Table 1. Differences between obesity, lipoedema, and lymphoedema

	Obesity	Lipoedema	Lymphoedema
Unilateral	Never	Never	Often
Bilateral	Always	Always	Not always
Symmetrical	Always	Always	Infrequently
Feet	No	No	Usually
Trunk/face	Yes	No	Yes
Effect of weight loss	Yes	Minimal	Possible
Childhood	Yes	No (not obvious)	Yes
Male	Yes	No (unless hormonal abnormalities)	Yes
Bruising	Mild	Moderate/severe	No
Tenderness	Mild	Moderate/severe	No
Stemmer's	Negative	Negative	Positive
Pitting	Absent	Absent	Yes
Skin consistency	Normal	Normal/very soft	Thicker and firmer
Pain	No	Yes	Uncomfortable

Source: Mortimer and Gordon, 2015

and allied health professionals, such as physiotherapists and occupational therapists, are appropriately trained to assess, diagnose, and advise patients on the best possible treatment to manage and prevent further progression (Fetzer and Fetzer, 2015; Hardy, 2015). Provision of clinics across the UK is variable, although Lipoedema UK is compiling a register of UK NHS and private clinics that treat lipoedema. It can be possible to be referred to a clinic outside a patient's normal treatment area. The Lymphoedema Support Network (LSN) has advocacy packs that provide guidance on whether this treatment avenue is appropriate. Lymphoedema clinics are important because, as well as advising patients on the best possible treatments, they can measure patients for specialised compression garments and monitor the progress of the condition at appropriate intervals. However, not all lymphoedema clinics will see lipoedema patients.

Irrespective of whether or not lipoedema services are available, there are several key ways in which generic health professionals (e.g. practice or community nurses) can help lipoedema patients manage their condition. These are:

- ◆ Encouraging healthy eating
- ◆ Carrying out low-impact exercise and improving general fitness
- ◆ Wearing compression garments
- ◆ Undergoing simple lymphatic drainage
- ◆ Providing psychological support.

This article will now describe each of these techniques in relation to the treatment of lipoedema. It is important to bear in mind that there is no set evidence-based treatment known yet, and it is vital that health professionals carry out a differential diagnosis for each patient. There are clinically proven treatments for related conditions, such as lymphoedema and obesity; however, these treatments cannot always be transferrable for lipoedema management.

Healthy eating

One of the markers of lipoedema is that lipoedematous fat is minimally reduced by dieting (Lipoedema UK, 2013). About 95% of people with lipoedema report that they fail to lose weight in areas affected by lipoedema, despite losing weight successfully in other areas (Lipoedema UK, 2013).

If patients with lipoedema are overweight, it will exacerbate the underlying condition; therefore, patients should be encouraged to try and lose the excess weight (Wise 2013; Hardy 2015), as well as practice healthy eating, as it is a part of any fitness programme (Hardy, 2015). Additional weight gain can also lead to the condition worsening or progressing to lipo-lymphoedema (Todd, 2010). Maintaining mobility is very important for people with lipoedema as this allows them to continue living as full a life as possible, and excess fat on top of adipose tissue can seriously affect mobility, as well as lead to other obesity-related health issues (Todd, 2010).

Some lymphoedema nutritionalists recommend the Harvie and Howell (2014) 'two-day' diet, as they have noticed patients appear to experience easier, longer lasting weight loss using this programme (Hardy, 2015). The 2-day diet involves following a restricted, low carbohydrate, 1000 calorie diet for two consecutive days a week, and eating a healthy Mediterranean-style diet for the other five, non-restricted days. The diet has been popularised by Dr Michelle Harvie after her research (Harvie et al, 2013) found that a low carbohydrate, calorie-controlled diet for 2 days a week was more effective at losing excess weight for breast cancer patients than eating fewer calories every day.

Anecdotally, patients have reported finding other diets, such as the Rare Adipose Disorders (RAD) diet or anti-inflammatory diets helpful; however, there is no evidence to demonstrate the effectiveness of a particular diet on lipoedema.

The lack of clinical evidence implies that health professionals tend to recommend standard healthy eating regimens with moderate carbohydrates, sugars, and fats. Patients have reported that simple carbohydrates, such as white flour in white bread, pasta, and cakes, tend to have an adverse effect on the retention of fluid, and thus, some patients find it helpful to avoid these. Patients also report that avoiding wheat, wine, yeast, red meat, and processed foods can be helpful. However, again, there is no clinical evidence to support this.

Low-impact exercise

It is very important to keep the lymph moving and stay as active as possible. Areas affected by lipoedema may not reduce significantly with exercise, but exercise may help tone muscles and burn calories, stopping excess weight gain. Exercise also promotes feelings of wellbeing (Salmon, 2001; Penedo, 2005), which is especially important for lipoedema patients whose self-esteem, confidence, and mood is often negatively affected by the condition (Todd, 2010; Lipoedema UK, 2013).

However, people with lipoedema should be careful when carrying out high-impact exercises, such as running, ball sports, and aerobics, as these activities can place an additional strain on the knees or can lead to bruising, which is common in lipoedema. Patients with lipoedema appear to experience a high level of knee pain, and many show symptoms of degenerative knee changes. Therefore, excessive high-impact exercise can aggravate these symptoms, possibly causing worsening of the condition. It is important though not to stop doing something that the patient loves, but the patient would need to consider doing it in moderation.

Aqua exercise

Water-based exercise has been shown to elicit significant health benefits in many populations, ranging from increased cardiovascular function to improvements in body fat (Tsourlou et al, 2006; Volaklis et al, 2007).

Exercise in water has been found to be especially helpful for controlling lipoedema, with 79% of patients reporting that it helps their lipoedema, from dramatic reductions in limb size, to relief at the freedom of movement and weightlessness that the water provides (Lipoedema UK, 2013). People who exercise in water regularly report reductions in pain and limb size (Lipoedema UK, 2013), with marked improvements in the loose, often floppy tissues of their arms and legs.

The hydrostatic pressure exerted on the human body when in water aids blood circulation, helps prevent blood pooling, and improves blood return from the extremities, which means kidneys will work more efficiently during exercise. Moreover, because water is approximately 800 times denser than air, pool-based exercise allows for high levels of energy expenditure with relatively little strain on the body (di Prampero, 1986).

Patients do not need to be able to swim, just walking in water is helpful; the deeper you are in the water, the higher the water pressure. This pressure helps the circulation and reduces fluid in the legs. Exercise in water is especially

beneficial because in chest-high water, the body feels weightless and buoyant, which relieves pressure on the joints.

Glenda Baum, an aqua aerobics pioneer, advises on how to work out in the water (Baum, 2015): 'To work aerobically, you need to get a little breathless; use your arms and legs together in bigger movements. Swimming is great, but as you are at the surface, there is not nearly as much water pressure, so aqua aerobics or walking is better. Avoid breast stroke, as it is bad for knees and necks. Front or back crawl is alright.'

Deep breathing

Deep abdominal breathing is also believed to be beneficial as it enhances the intake of oxygen into the blood circulation and promotes the passage of lymph throughout the lymphatic system (Mortimer and Todd, 2015; Wallace, 2015). Lymphatic yoga may also be beneficial and a study is currently underway with lipoedema patients to ascertain whether regular sessions reduce the size of the limbs and level of discomfort and improve patient wellbeing (Wallace, 2015).

Remedial exercises

Remedial exercises, such as those recommended by physiotherapists to strengthen and improve muscle tone in the legs and around the knees, could be helpful, as knees are often under strain from additional weight on the lower limbs. Sitting and standing for long periods without a break should be avoided as it will lead to a build up of fluid.

Overcoming barriers

Embarrassment about their appearance and a lack of confidence can be a big barrier to many women undertaking exercise with lipoedema. Women-only classes or taking along a friend or relative for support can be a less-threatening way to try new activities. Research has shown that people who exercise with someone else perform better in the exercise across multiple sessions (Irwin et al, 2012).

Compression garments

Compression garments and hosiery, such as socks, stockings, tights, leggings, capri pants, and arm sleeves, should be worn as much as possible, ideally all day (Hardy, 2015) (Figures 1 and 2). If patients are resistant, recommend wearing garments in scenarios where support is needed more acutely and will provide the most benefit, such as during exercise, standing, or travelling (Hardy, 2015). Compression garments and hosiery are important to reduce any fluid (oedema) in the tissues by promoting venous and lymphatic drainage. They also support the limbs by lifting and streamlining uneven appearance. They can help to reduce the pain, discomfort, and aching so often associated with lipoedema, with 55% of patients reporting that bandaging helped with pain and discomfort (Lipoedema UK, 2013). Compression also helps prevent the progression of lipoedema to lipo-lymphoedema, and if lipo-lymphoedema has developed, then compression is essential (Todd, 2010).

The measuring and fitting of compression hosiery is a specialist area, and it is important that women are

prescribed the correct garment, in the most appropriate fabric, compression strength, and style for their individual needs. A full assessment of the patient, including vascular circulation, should be undertaken. The severity of the condition needs to be taken into consideration, as well as the age of the patient, lifestyle, other associated medical conditions, in addition to the patient's ability to apply and remove garments. Owing to the size and shape of the limbs, many women with lipoedema require a bespoke made-to-measure garment for optimum fit, greater comfort, and enhanced compliance (Hardy, 2015).

A recent garment survey confirmed that only 50% of all patients issued with garments found them helpful. This was mainly due to poor measuring techniques. Those who had garments issued through lymph clinics (with health professionals who had training) had a better experience (Hardy, 2015).

Most garments are now available on GP prescription, but occasionally, patients have not been issued with the garments they have been prescribed because of miscommunications/misunderstandings between the GPs and pharmacies, or a lack of stock at local pharmacies/distributors (Hardy, 2015). One way to avoid this issue is to use a specialist prescription mail order service, such as the Daylong Dispensing Service, which ensures the prescription recommendation is followed, and who will follow up with the prescriber if anything is unclear (Hardy, 2015).

Issues with application

The application of garments is an equally important aspect of care, especially as many patients struggle with mobility, which can make reaching down to put on stockings extremely challenging. There are a number of applicators available that can help people to apply and remove garments. It has been recommended that 'every lipoedema patient should have well-fitting rubber gloves and matting in their handbag,' to help with application (Hardy, 2015). The best outcomes are achieved when patients are able to apply their own garments and distribute the material evenly, so including this step

in garment measurement is as important as choosing the correct garment (Hardy, 2015).

Patients should also be told when to remove garments, should problems arise. This may include circulation issues, such as discoloured digits, pain, or pins and needles. Garments should be removed immediately in such cases.

Compression garments are expensive, and advice needs to be given on how to care for and launder the garments to prolong their use and durability. All compression garments should be replaced every 4 to 6 months (depending on the make-up of the fabric) and the size, style, and strength of the garment reviewed accordingly (Hardy, 2015).

Self-lymphatic drainage

Manual lymphatic drainage (MLD) is a gentle, specialised form of massage carried out by specialist practitioners, and is used in combination with compression garments, exercise, and multilayer bandaging in the treatment of lymphoedema and similar conditions. Lymphatic drainage is useful for patients with lipoedema, because the pressure the condition can put on the lymph system can cause lipo-lymphoedema (Todd, 2010). This occurs when the capacity of the lymphatic system is reduced to such an extent that it is unable to perform one of its basic functions: the removal of water from the tissues. This means that fluid will accumulate and oedema develops in addition to lipoedema. MLD consists of very light, rhythmical, and pumping hand movements to gently stretch the skin and stimulate the lymphatic system to drain more efficiently.

Unfortunately, the provision of MLD within the NHS varies depending on local-funding decisions (Hardy, 2015); hence, many patients choose to seek this treatment privately. However, it is important to find a therapist who is suitably trained in this technique.

Patients can also carry out a simple form of lymphatic drainage on themselves, known as self or simple lymphatic drainage (SLD). It is relaxing and simple to learn, and if practised for about 10 minutes daily, can enhance lymph flow and may help to relieve some of the discomfort and congestion in the limbs. It can also help patients feel they are playing a positive role in helping to control their own condition. MLD or lymphoedema practitioners can teach patients a suitable SLD self-massage routine. The Lymphoedema Support Network (LSN) also produces videos demonstrating this technique.

Psychological support

Although the provision of lipoedema/lymphoedema clinics and care is hugely variable throughout the UK, one area where GPs often can help is through referral for counseling (Pledger, 2015).

Traditionally, lipoedema patients have rarely been referred for counseling, even though 85% of women say that lipoedema affects their mental health and ability to cope with life (Lipoedema UK, 2013). Moreover, 85% said their body shape had led to low self-esteem, while many also report a lack of confidence, depression, self-harm, eating disorders, and suicidal thoughts (Lipoedema UK, 2013).

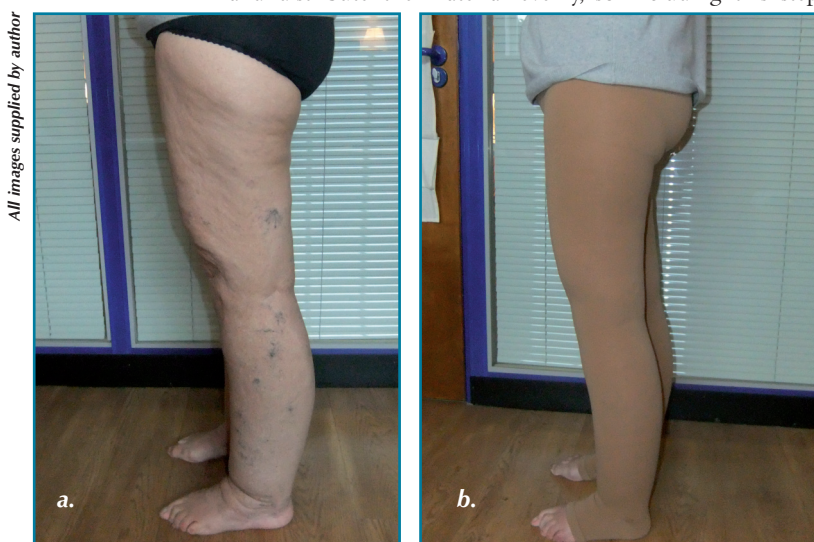


Figure 1. Lipoedema patient (a) without and (b) with compression. The compression provides smoother and streamlined support.

Counseling and support can help patients deal with this. Lipoedema UK is a hugely valuable information resource, and it can also provide GP information packs. Online patient support groups, such as Talk Lipoedema and Lipoedema Ladies, allow patients to share experiences, so they feel less isolated and alone in their experience with the condition.

Women should also be encouraged to explain the condition of lipoedema to friends, family, and their social network so that the people around the patient understand it and do not blame the condition on the patient. Lipoedema is not caused by lifestyle or diet (Langendoen, 2009; Todd, 2010). With such low awareness of the condition in primary care (Lipoedema UK, 2013), patients are also advised to help educate their health professionals such as GPs and nurses, so they can organise referrals to specialist treatment centres.

Citing peer-reviewed articles such as Fetzer and Fetzer (2015) or Todd (2010) can be helpful in providing credible material to share with health professionals. Lipoedema UK also produces a GP information pack as well as a handbook for health professions and patients. Encouraging GPs to take the online GP e-learning Lipoedema course is also advised.

Conclusion

Although the lack of a cure can make patients feel frustrated and hopeless, patients with lipoedema should be encouraged to take an active role in managing their condition. Quality of life can be significantly improved through self-management techniques, and the earlier that patients introduce these techniques, the better the outcomes that can be achieved. Self-management techniques also complement specialist treatments, such as MLD; intermittent pneumatic compression therapy (IPC); multilayer bandaging; and, where appropriate, liposuction (Rapprich et al, 2011; Schmeller et al, 2012). These specialist treatments will be discussed in a future article. Providing support and giving these patients concrete tools that can help them to manage their condition is an important and rewarding role.

BJCN

Declaration of interest: Both authors are volunteers for the charity Lipoedema UK.

Note: Nurses interested in undertaking approved lymphoedema training programmes can find details of the training courses on the British Lymphology Society (BLS) website: www.thebls.com.

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Figure 2. Lipoedema patient shown (a) without compression hosiery support and (b) with it.

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KEY POINTS

- ◆ There is currently no cure for lipoedema, but self-management techniques can help to manage the condition and prevent its progression
- ◆ A sensible, healthy-eating programme designed to lose any excess weight and to prevent further weight gain is advised
- ◆ Following an appropriate exercise schedule to build muscle tone will help maintain mobility, weight, and improve mood
- ◆ Wearing appropriate, graded compression garments to support the tissues and reduce oedema (fluid build up) will help prevent progression