

Early lipoedema diagnosis and the RCGP e-learning course

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Frequently misdiagnosed as obesity (Todd, 2010), lipoedema is an adipose tissue disorder estimated to affect up to 11% of the female population (Foldi and Foldi, 2006; Fonder et al, 2007). Despite this, only 5% of GPs have the skills and knowledge to diagnose it (Lipoedema UK, 2013). In lipoedema, excessive fat distribution occurs predominantly from the waist down, resulting in the lower limbs becoming disproportionately larger than the upper torso (Langendoen et al, 2009). This is often an important characteristic feature of lipoedema, whereas, in generalised obesity, excessive fat distribution occurs all over the body.

Lipoedema is rarely recognised in primary care and is therefore under-diagnosed (Goodliffe et al, 2013). In light of this, the charity Lipoedema UK's has partnered with the Royal College of General Practitioners (RCGP) and health professionals to provide the first-ever e-learning course on the diagnosis and management of lipoedema. It has been endorsed by the Royal College of Nurses and is free to all health professionals in the UK.

The RCGP e-learning course aims to enable GPs, nurses and other health professionals to make an accurate diagnosis so that patients do not experience years of doubt

and unnecessary suffering before the relief of diagnosis. The course describes the presentation, pathophysiology, diagnosis and management of lipoedema in primary care. It is available on the RCGP website (www.elearning.rcgp.org.uk/lipoedema).

What is lipoedema?

Lipoedema was first identified in 1940. However, prior to the launch of the e-learning course in 2014, lipoedema has been a poorly understood, frequently misdiagnosed and rarely recognised condition, as it is rarely taught to medical students or GPs (Goodliffe et al, 2013) or documented in medical textbooks (Wise, 2013).

Lipoedema is a chronic, genetic fat disorder that, it seems, often affects more than one family member (Todd, 2010; Lipoedema UK, 2013), although further research is needed to investigate the genetic element further. It appears to be linked to the female hormone oestrogen and predominantly affects females—it is exceptionally rare in males (Langendoen et al, 2009).

A defining trait of lipoedema is that lipoedemous fat responds very poorly to diet and exercise, and weight loss may occur only in areas of the body not affected by lipoedema (Todd, 2010). In some cases, excessive weight loss may exacerbate the difference between a slender upper and larger lower torso (Wise, 2013).

Presentation

Lipoedema presents as a bilateral symmetrical enlargement of the lower (and in some cases) the upper extremities, often resulting in a significant disproportion of the waist-to-hip ratio (Langendoen et al, 2009). The condition progresses over time, so initially this disproportion is less marked, making the condition harder to identify, especially as clinical photographs are often of long-standing lipoedema (*Figure 1*). In the early stages, the only obvious marker can be the disappearance of the concave spaces on both sides of the Achilles tendon (Langendoen et al, 2009). The feet are rarely affected, often resulting in a fatty 'cuff', sometimes described as a 'bracelet' or 'elastic band' at the ankles (Langendoen et al, 2009). Lipoedema can sometimes develop in the arms, but very rarely affects the forearms or hands. The hips and knees in particular can also become painful. Areas such as knees, hips, thighs and buttocks develop distinctive pads of fatty

ABSTRACT

Frequently misdiagnosed as obesity, lipoedema is chronic condition involving an abnormal build-up of fat cells in the legs, thighs and buttocks that cannot be shifted by exercise or dieting. Estimated to affect up to 11% of the female population, the condition is widely unknown by health professionals. This means women typically wait for many years before diagnosis. This allows the condition to progress unchecked, resulting in unnecessary deterioration and the development of associated comorbidities, as well as significant pain and mental anguish. A free, 30-minute Royal College of General Practitioners (RCGP) e-learning course created in partnership with Lipoedema UK aims to rectify this situation by educating nurses, GPs and other health professionals on how to diagnose and manage lipoedema in primary care. This article aims to describe the condition of lipoedema, how to recognise/diagnose it, current treatment options and the findings of a 240-patient survey carried out by Lipoedema UK in 2013 that included documenting the difficulties for patients in obtaining a diagnosis as well as the mental and physical effects of the condition.

KEY WORDS

- ◆ Lipoedema ◆ Obesity ◆ E-learning ◆ Training ◆ Misdiagnosis
- ◆ Lymphodema



Figure 1. Mild (left) moderate (centre) and severe (right) lipoedema

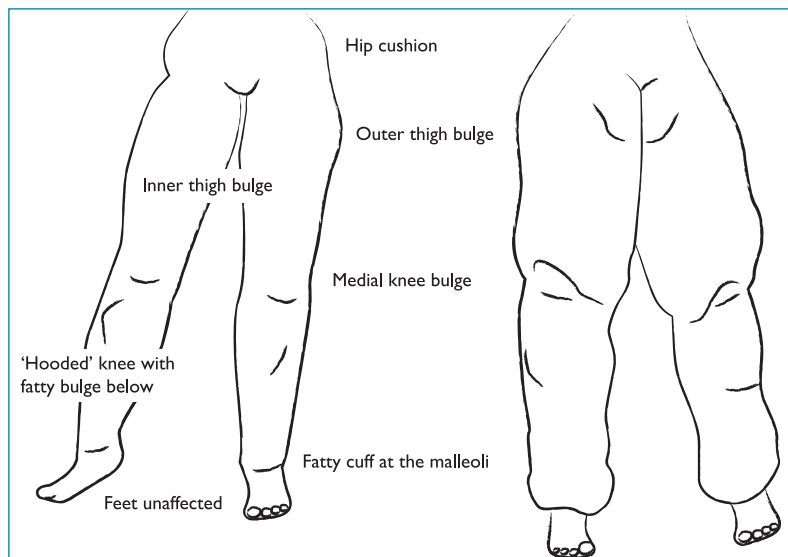


Figure 2. Line drawing of common features of lipoedemous legs

Box 1. Five ways to spot lipoedema

- ◆ Hips, buttocks and legs are out of proportion with the rest of the body. Upper arms may also be out of proportion
- ◆ Symptoms usually appear at puberty, before which the body appeared normal. In rare cases, it can also appear at other times of hormonal change such as hormonal contraception, pregnancy or menopause
- ◆ Lipoedema fat often hurts when banged or scraped gently, and bruises easily. The lower limbs can feel frequently tender and painful to even the slightest touch
- ◆ Lipoedema looks and feels different to normal body fat—it is softer and dimpled, like cellulite
- ◆ Obesity responds well to diet and exercise and weight loss is experienced from all areas of the body. With lipoedema, weight loss will occur from the upper body but minimal improvement will occur in affected areas below the waist

Source: Wise (2013)

tissue, which become noticeably bigger than the rest of the body (Figure 2). The tissues in lipoedemous areas can appear to be very loose and floppy (Wise, 2013).

The excess adipose deposits are frequently tender and painful in nature and often respond poorly to diet and exercise (Langendoen et al, 2009; Todd, 2010). The affected skin may be pale and cool to the touch, and bruising can occur easily and spontaneously without apparent cause (Wise, 2013).

As Wise (2013) notes, this is because the blood capillaries surrounding fat cells in lipoedema are particularly fragile and hyper-permeable. As a result, protein molecules leak out of the capillaries into the intercellular spaces between the fat cells. Proteins have the ability to attract additional fluid, and this causes the minute lymphatic vessels within the layers of fat to work at a higher level to remove excess fluid. Eventually, the lymphatic vessels become overloaded and can no longer cope with the excess fluid that needs to be transported. Consequently, oedema develops between the fat cells, resulting in increased pressure and inflammation in the tissues and, in turn, pain and discomfort (Wise, 2013).

Lipoedema develops symmetrically on both sides, unlike lymphoedema, which usually affects only one side (Langendoen et al, 2009). See Box 1 for a breakdown of some straightforward indicators of lipoedema.

Effect of puberty or hormonal change

In 78% of women (Lipoedema UK, 2013), lipoedema first appears during puberty, when sufferers become aware of the differences between their body shape and that of their peers. It can also develop or worsen at periods of significant hormonal change, such as hormonal contraception, pregnancy or menopause.

Under-diagnosis

As lipoedema is frequently misdiagnosed as obesity or lymphoedema, patients often embark on an endless cycle of diet and exercise programmes that fail to help, and often lead to physical and psychological harm (Todd, 2010; Lipoedema UK, 2013). Women are commonly told that they are obese, overweight or fat and that they need to lose weight (Forner-Cordero et al, 2012; Lipoedema UK, 2013). Some become anorexic as a result of extreme weight loss in an attempt to manage the situation (Lipoedema UK, 2013). Inappropriate advice promotes self-blame, lowers self-esteem and denies access to correct diagnosis, treatment and prevention of deterioration (Todd, 2010; Lipoedema UK, 2013).

The RCGP e-learning course (Box 2) is therefore crucial as it educates nurses and other health professionals to recognise and diagnose this progressive, debilitating and disfiguring condition.

Nurse involvement and survey

Lipoedema UK's Big Survey, launched with the support of Professor Peter Mortimer, the lymphoedema team at St George's Hospital and the British Lymphology Society, has provided valuable data on the issues affecting women with lipoedema.

Completed by 240 women, the survey found that only 5% of patients were diagnosed by their doctor. The majority (44%) were diagnosed by a lymphoedema nurse specialist, showing the key role specialist nurses play in identifying the condition (Figure 3).

However, despite most people developing the condition in puberty, the survey found that the lack of knowledge about the condition within primary care has meant that it often takes several decades before women obtain a correct diagnosis. The survey found that the average age of diagnosis was 44 years of age. Most women only received their diagnosis when the condition was well advanced and with other associated comorbidities, despite describing their symptoms to numerous health professionals over the years.

Common comorbidities include lipo-lymphoedema (where the lipoedemous fat cells have obstructed the lymphatic pathways to cause secondary lymphoedema) and obesity.

The problems of misdiagnosis

The survey found that poor awareness of lipoedema by health professionals was responsible for causing many years of unnecessary physical and emotional suffering. The survey revealed the lack of medical knowledge about the condition meant many lipoedema sufferers found doctors to be dismissive and in some cases, rude. Survey responses included patients being told:

‘That I was delusional about my eating habits, and [I] was accused of lying about my food diary. Generally each doctor I saw thought it was food and laziness related.’

“‘Face facts. You’re FAT. Stop wasting my time and yours and go to a gym.’ He didn’t examine me, went back to his paperwork, didn’t look at me or say goodbye.’

‘I was 18 then and it made me feel small, insignificant and humiliated—that I had “wasted” the doctor’s time. It has taken me another 25 years to dare to mention this again to any medic for fear of the same.’

The survey revealed that these types of experiences were common. The impacts that these reactions and the lack of diagnosis had on people were just as traumatic. Respondents were often hurt, with comments including:

‘I was insulted and embarrassed. It took a lot of guts to show myself to anyone and my legs were so painful. I tried to explain that I had constantly been dieting but only the top part of me got smaller but he didn’t listen.’

‘It destroyed any self-esteem I had by making me think that the symptoms were my fault; my inability to lose weight was my fault. That the doctors and other professionals I saw just looked at me as another fatty and didn’t actually look at, and see, me at all.’

The relief of diagnosis

Conversely, the relief patients expressed when they finally received a diagnosis is tremendous, highlighting the urgent need for GPs, nurses and other health professionals to take the RCGP e-learning course. Comments included:

‘To be spoken to as a patient with an illness made a huge difference. To be helped to manage the condition made me look at my own body in a different way for the first time in possibly 50 years.’

Box 2. The RCGP e-learning lipoedema course

Launched in June 2014, the 30-minute course covers the presentation, pathophysiology, diagnosis and management of lipoedema in primary care through the use of case scenarios, videos, and quizzes helping learners to:

- ◆ Explain the differences between lipoedema, lymphodema and general obesity
- ◆ Recognise the psychological impact of lipoedema on the patient
- ◆ Advise patients on the management of lipoedema including the use of compression and consideration of surgical techniques
- ◆ Advise patients where they can access accredited and evidence based resources on lipoedema.

Free to UK health professionals, the online course will ensure that all of UK’s 60 000 GPs and 400 000 nurses will be able to improve their knowledge about the disease and enable women suffering from this condition to get recognition, diagnosis and treatment much earlier in their disease pathway, ensuring they get the desired support to maintain their physical and emotional health.

To date, 420 health professionals have accessed the course, and 96% have demonstrated improved knowledge on completion.

The course is available at www.elearning.rcgp.org.uk/lipoedema

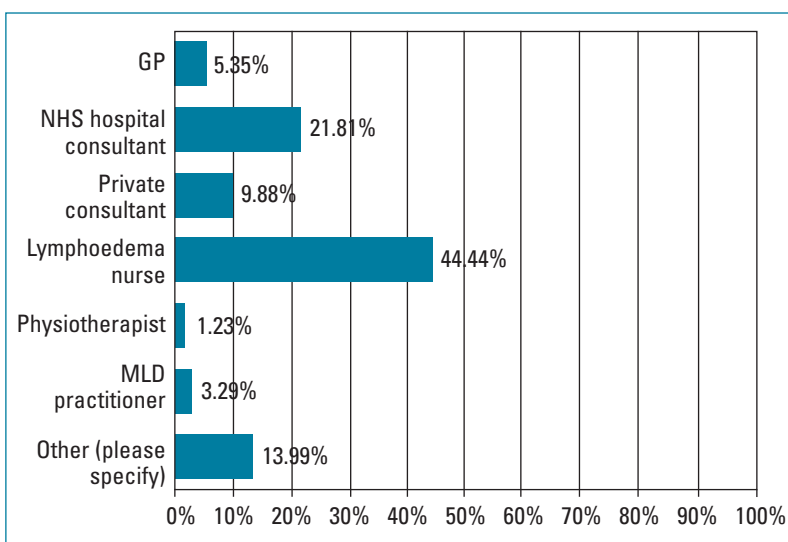


Figure 3. Results of Lipoedema UK Big Survey question ‘who diagnosed your lipoedema?’

'I am very grateful that I have at long last found out what my "illness" is and just pray and hope that a cure will be found very soon. Also so grateful that I have managed to find Lipoedema UK.'

'It was wonderful to be listened to, and taken seriously and to be treated with compassion, caring and dignity after being ignored and dismissed for 50 years.'

Destroying lives

The results of the Lipoedema UK survey gave a very clear picture of the struggles faced by women with lipoedema, with significant impacts reported in the following areas.

Mental health

Some 85% of women said that lipoedema affects their mental health and ability to cope with life: 85% said their body shape had led to low self-esteem, while many also reported effects such as a lack of confidence, depression, self-harm and suicidal thoughts.

Careers

Some 51% of respondents reported that their lipoedema had an impact on their ability to carry out their chosen career.

Mobility

As lipoedema progresses it can have a severe effects on mobility, with 55% of sufferers reporting that their body shape had led to restricted mobility.

Relationships

Many women also commented on the effect their condition had on their relationships. A total of 60% said it restricted their social life; 50% said restricted their sex life. The quotes below demonstrate some of these effects:

'The psychological damage of this condition is just as painful to deal with as the physical elements. Feeling alone and most people, including most doctors, assuming I am lazy, greedy and fat.'

'It's depressing, restricts my life. I just wish my body was less disgusting.'

'I know I do not want to and cannot live like this, it's soul destroying. I try to remain positive, but on days when I can barely move because of the pain, it is very, very hard to even bother getting up and facing the world knowing they do not understand.'

'It makes me lose hope in anything ever working for me. I've tried so hard in the past, doing everything you are "supposed" to do to lose weight, and nothing ever works, and this feeling transfers to other areas of my life, making me feel that it doesn't matter how hard you try, nothing ever works, so you

might as well give up.'

'I have low self-esteem and hate to look at myself. Hard to cover up. People judge you when they don't know. I feel like wearing a sign saying I'm not obese, I have a medical condition people are unaware of. I miss swimming and have lack of energy through pain; exercise is hard with nothing achieved at the end of it anymore. I want to win the battle of it but don't see how.'

Improving diagnosis timeframes should considerably improve the emotional impacts on lipoedema sufferers, at least removing much of the agony of blame and self-doubt. It also means that sufferers can start to manage their condition earlier, slowing progression to maintain a better quality of life for longer.

Treatments for lipoedema

As yet, there is no proven cure for lipoedema. However, much can be done to help improve symptoms and prevent progression. Much of this can be done by patient self-care if advised correctly. Significant improvements can be achieved by following a sensible, healthy eating programme designed to lose any excess weight and prevent further weight gain (Langendoen et al, 2009). Following an appropriate exercise regime to build muscle tone and wearing appropriate, graded compression garments to support the tissues and reduce oedema (fluid build-up) will help to maintain an active lifestyle (Langendoen et al, 2009; Wise, 2013; Lipoedema UK, 2014).

Advice for community nurses

There are several key ways that health professionals can provide effective treatment for lipoedema.

Service from trained professionals and referrals

Lipoedema services now exist in some lymphoedema clinics. Lymphoedema nurses and allied health professionals, such as physiotherapists and occupational therapists, are appropriately trained to assess, diagnose and advise patients regarding the best possible treatment to manage and prevent further progression. Lipoedema UK is compiling a register of UK NHS and private clinics that treat lipoedema.

Compression therapy

Compression garments and hosiery, such as socks, stockings, tights, leggings, capri pants and arm sleeves are important to reduce any fluid (oedema) in the tissues by promoting venous and lymphatic drainage. They also support the limbs, lifting and streamlining uneven appearance, as well as helping to reduce pain and discomfort. Lymphoedema nurse specialists are trained to advise on the type, strength and style and it is essential that garments are correctly prescribed to avoid circulatory problems (most garments are now available on GP prescription). This includes taking specific measurements to ensure a good fit so that they are comfortable to wear.

Manual lymphatic drainage

Manual lymphatic drainage (MLD) is a specific type of gentle massage that is used to stimulate lymphatic flow, thereby helping to reduce oedema, pain and discomfort. It is most effective when combined with other treatments such as compression bandaging and/or compression garments. Qualified practitioners can be found at www.mlduk.org.uk.

Simple lymphatic drainage

Simple lymphatic drainage is a simplified version of MLD that can be self-administered by patients to help to reduce swelling and relieve discomfort and pain. The Lymphoedema Support Network provides support and information on managing lymphoedema and produces videos demonstrating the technique.

Dietary advice

A well-balanced healthy diet, with normal-sized portions, and avoiding over- or under-eating is extremely important as lipoedema is exacerbated by obesity. Although there is no proven connection, many people find that certain food and drink, such as wine, wheat and spicy or processed foods seem to affect their symptoms and that avoiding these foods can help control swelling and discomfort.

Exercise

Exercise is important to help maintain a healthy weight, and it also leads to feelings of wellbeing. However, aerobic activity can aggravate lipoedema, so non-aerobic choices are important. Swimming or aqua exercise (the ability to swim is not necessary), walking and cycling are non-aerobic and among the most beneficial exercises for reducing and controlling areas with lipoedema. Exercise in water is especially good for controlling lipoedema, and many people who do this regularly report reductions in pain and size (Lipoedema UK, 2013), with marked improvements to the loose, often floppy, tissues of their legs and arms.

Referral for liposuction

Tumescent liposuction can benefit patients with lipoedema

and, to date, it is the only method where results on patients with lipoedema have been fully evaluated with results published (Rapprich et al, 2011; Schmeller et al, 2012). This is not a cure for lipoedema, and compression garments may still need to be worn 24 hours a day for the remainder of patients' lives. Liposuction can only be undertaken for lipoedema if morbid obesity weight is fully controlled. Traditional liposuction is not recommended as it results in surgical traumatisation, especially to the lymphatic vessels, which can lead to lipo-lymphoedema and a worsening of the symptoms. Inappropriate liposuction or plastic surgery can be very damaging and lead to complications and deterioration of the disease.

To help nurses and other health professionals to recognise and understand lipoedema, and to help women with the condition, Lipoedema UK has produced a booklet for women and health professionals. Copies can be ordered from info@lipoedema.co.uk using the reference BJCN LUKW&HCP002.

Conclusion: the future of lipoedema treatment

Lipoedema is a challenging condition—both for patients and health professionals. However, Lipoedema UK's survey highlights the key part that health professionals play in shaping patient experience. Many respondents commented on the positive and, in some cases, life-changing experiences they had had with nurses who understood their condition and treated them with empathy. Education is key to ensuring more women are treated by professionals who can recognise and understand their condition and advise them accordingly. The RCGP course provides the knowledge so desperately needed. With this education, there is hope to that enough momentum will be created to spark research into finding a cure.

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KEY POINTS

- ◆ Lipoedema is an adipose tissue disorder whereby excessive fat distribution occurs predominantly from the waist down, resulting in the lower limbs becoming disproportionately larger than the upper torso
- ◆ Lipoedema is estimated to affect 11% of women but is frequently misdiagnosed as obesity; however, unlike with obesity, lipoedema fat does not respond to dieting or exercise, and is often painful and tender
- ◆ Only 5% of GPs have the knowledge to diagnose lipoedema, and training for all health professionals is vital to ensure faster diagnosis
- ◆ The RCGP's 30-minute lipoedema e-learning course is free to UK health professionals and describes the presentation, pathophysiology, diagnosis and management of lipoedema in primary care
- ◆ Find out more information at Lipoedema UK: www.lipoedema.co.uk