



Lipoedema

Patient Education Booklet



What is Lipoedema?

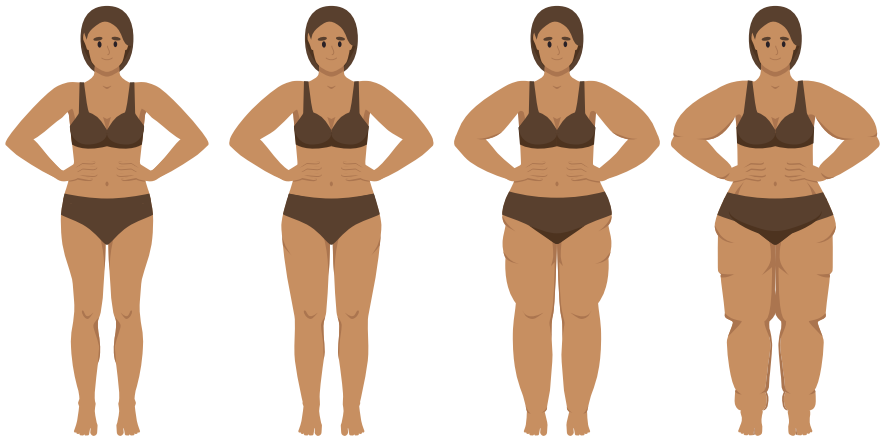
Lipoedema is a chronic (long-term) condition that causes an abnormal build-up of fat cells in your legs, thighs and bottom. It can also affect your arms. It can make you look out of proportion with the rest of your body and often does not affect the feet or hands.

There is no cure for lipoedema, but with the right treatment and care, the symptoms can be managed well.

Lipoedema almost exclusively affects women, and it often develops when hormones are changing – for example, during puberty or menopause.

Lipoedema is different from lymphoedema. They both cause increase in size of the affected area, but lipoedema is a build-up of fat and lymphoedema is a build-up of fluid.

Lipoedema Presentation



How might lipoedema affect me?

Lipoedema can change how you look, and it can affect your mobility. There can be tenderness in the affected area but not always. The unusual distribution of fat can lead to changes in your joints, which also can be painful. This may make it harder for you to exercise and to work.

Living with a long-term condition that affects your appearance can affect your mental health. It can lead to a negative body image, low self-esteem, stress, fatigue and eating disorders.

What's the difference between obesity, lymphoedema and lipoedema?

Many people have more than one of these conditions. As many as 85% of people living with lipoedema are also living with obesity, lipoedema does not cause lymphoedema but people with both conditions can develop lymphoedema.

It can be difficult to separate these conditions unless clinically assessed, and lipoedema is often misunderstood or misdiagnosed. Therefore, it's likely that many cases go unreported.

Obesity

Obesity is a condition where your weight affects your health. It is a long-term (chronic) condition with a wide range of causes. It usually develops over time.

Obesity is diagnosed when you have a high BMI and health problems linked to your weight. People with a BMI of 30Kg/m² or more have a high risk of obesity.

If you have a high BMI, with risk of other health problems, then you may be referred to an obesity management programme to help you reach a 'best weight'. This is a weight you can maintain, while living the healthiest and happiest life that is sustainable and enjoyable. This may include medications, injections or bariatric surgery.

Learn more about living with obesity from the Centre for Obesity Management website <https://schcom.ie/> and the Irish Coalition for People living with Obesity <https://icpobesity.org/>.

Lymphoedema

Lymphoedema is a build-up of protein rich fluid due to damage or over load to the lymphatic system.

Lipoedema

Lipoedema is a build-up of fat in the legs, bottom, and sometimes the arms that is not in proportion with the rest of the body. It does not usually affect men, unlike lymphoedema or obesity.

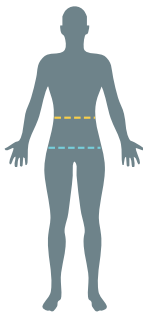
There can be tenderness over the skin thought to be caused by inflammation and a lack of oxygen in your fatty tissue.

It can be difficult to diagnose lipoedema, especially if you have a high BMI so it is important that your waist-to-hip ratio (the difference between your waist and hip measurements and waist to height ratio) is taken into consideration. Your lymphoedema specialist will be able to tell you if your waist-to-hip or waist to height ratio suggests that you have lipoedema.

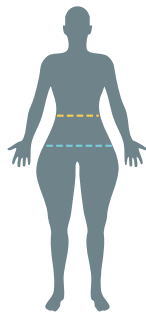
What causes Lipoedema?

We don't yet know what causes lipoedema, but it might be linked to hormones and genetics.

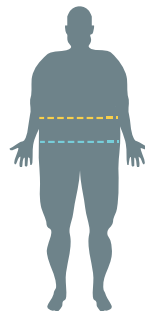
Lipoedema often starts with weight gain during a time of hormonal change – such as puberty, pregnancy or menopause, or when using birth-control pills. Some people notice they are experiencing signs and symptoms that are similar to those of a family member who has a lipoedema diagnosis, so researchers think genetics may be a factor.



Average



Lipoedema



Obesity

What does lipoedema look and feel like?

Lipoedema changes the shape and size of your legs, your bottom, and sometimes your arms. However, it doesn't affect your upper body, face, hands or feet. This can change your proportions, so your waist looks narrower and your hips and thighs look swollen. The changes are usually symmetrical on both sides of your body.

Lipoedema looks and feels different from normal body fat. It feels softer and cooler, and may be dimpled like orange peel.

The parts of your body that are affected feel painful and tender when you touch them, because they are inflamed. If you have depression or anxiety, this can make the pain feel worse.

Recognising lipoedema

You might have lipoedema if:

- **The lower half of your body looks bigger compared to your top half, with a narrow waist and wider hips**
- **You have pain or discomfort in the skin of your legs or arms**
- **The areas affected are tender to touch**
- **Your hands and feet look normal, with no obvious changes**
- **Your ankles have become less defined and merge with your calves (you may know this as 'cankles')**
- **The swollen areas look dimpled and feel different from normal body fat (they may feel cool and soft to the touch)**
- **You get bruises in the swollen areas, often without knowing why**
- **Other women in your family have similar symptoms**



How do I get a diagnosis?

When you first notice any signs of **lipoedema**, go to your GP.

Your GP will examine you and ask about your medical history. There is no test for lipoedema, so they'll need to rule out other conditions that have similar symptoms.

Your GP may refer you to a relevant consultant to confirm the medical diagnosis.

How can I manage my Lipoedema?

While you are waiting for a diagnosis there are things you can do to manage your lipoedema:

- **Regular physical activity, see page 10 for more information.**
- **Eat a healthy balanced diet.**
- **If you are living with overweight or obesity, managing weight might ease your symptoms. You can learn more about managing weight and health refer to the reference at the back of this booklet on weight management.**
- **Learn about lipoedema. Understanding your condition is one of the most powerful things you can do to help manage it.**



Lipoedema Management

You can manage your lipoedema with treatment and self-care, which may include:

1. **Compression therapy, such as wearing compression sportswear or compression garments**
2. **Skin care (for example, by moisturising your skin every day)**
3. **Regular physical activity**
4. **Psychological support (for example, to help you set goals)**
5. **Achieving the best weight for you**

1. Compression therapy

Wearing compression garments (such as special leggings or pants) on the parts of your body that are affected by lipoedema can:

- **Reduce pain and discomfort**
- **Support your legs and arms**
- **Help you move more easily**

Although compression therapy does not change the size or shape of your arms or legs, it does help manage the condition. This is important to know because you may be disappointed when you first start wearing compression garments. We do not completely understand how compression therapy improves pain and discomfort, but it is thought that compression reduces the pain caused by inflammation and a lack of oxygen in your fatty tissue.

Compression therapy is more effective when you combine it with movement, because they both reduce inflammation in the body. Physical activity in water, like swimming or aqua aerobics, is especially helpful for managing your lipoedema symptoms.

Compression therapy is very safe for most people, but there are some exceptions. Your healthcare professional will tell you if it isn't suitable for you.

What type of compression therapy is best for me?

To start with, try using active wear with elastin of 30% or higher. Active wear is relatively easy to find in shops, is easy to get on and off and looks like 'normal' clothing.

If active wear doesn't help, try compression garments. These are special stockings, leggings, pants and other items of clothing that have different levels of compression. Which type and compression level is best for you will be advised by your lymphoedema specialist.

What do I need to pay attention to?

- Make sure you're wearing the garment correctly. If you notice pain, discomfort, changes in your skin colour, or tingling or numbness in your toes and fingers, try moving your arm or leg to adjust the compression. If that doesn't help, take the garment off and ask your lymphoedema specialist for advice.
- Look after your skin. Compression garments can make your skin dry. Dry skin may also make you more likely to get infections from small injuries, such as scratches or insect bites which can increase the risk of bacteria entering your skin, which may cause infections such as cellulitis.



2. Skin Care

Taking good care of your skin is important.

- Wash your skin every day, using a mild soap or cleanser that is moisturising and hypo-allergenic, and has a pH balance of around 5.5.
- Dry your skin carefully, taking special care with any folds in the skin.
- Use moisturisers that contain emollients with a pH of 5.5 as they coat your skin with an oily layer that stops it drying out (talk to your pharmacist about a suitable emollient).
- Disinfect and treat any cuts, scratches and insect bites as soon as you notice them.
- Check between any folds of skin carefully for any skin break down caused by rubbing or moisture (catching this early will help you avoid bacterial or fungal infections).



3. Movement and Activity

Movement is key to managing lipoedema. It will:

- Help you maintain a healthy weight
- Improve your emotional wellbeing

Take some time to think about:

- What the benefits of movement or physical activity would be for you
- What it would add to your life
- How ready you are to add physical activity to your day

To get more active gradually increase the number of days and the amount of time you are active for each day. Try to break up long periods of time spent sitting, for example when you're watching TV or using your computer. Start small and do something you enjoy:

- The best activities for lipoedema are water-based such as aqua aerobics, walking in water or swimming.
- Cycling, yoga and stretching are also helpful. You can do yoga sitting on a chair if this suits you better.



- Walking and Nordic walking (where you walk with poles for a full-body workout) are great low-impact options as they don't put too much pressure on your joints.
- Resistance training is another good option to build muscle, which is important for healthy bones and muscles and for physical function. It can involve using your body weight, resistance bands, dumbbells, kettlebells or gym equipment.

Whatever physical activity you choose, it's advised to wear your compression garments or gym leggings that have some compression support. If you're having problems with your mobility, speak to your physiotherapist.

4. Psychological Support

Lipoedema is a long-term condition. It might have already taken you a long time to get your diagnosis and find professional help. This journey can be exhausting and affect your mental wellbeing. You don't need to live with lipoedema on your own. There is support available, through:

- Talking to your lymphoedema specialist
- Joining a peer support group, links are available at the end of this booklet
- Learning about self-help tools and strategies for coping with a chronic condition. You can find out more about these on the HSE website: <https://www.hse.ie/eng/health/hl/selfmanagement/>



5. Managing your Health and Weight

Eating well, being active and sleeping well can help weight management, improve your quality of life and reduce your risk of weight related problems. Eating well means that you focus on eating regularly and spreading out your meals and snacks, eating nutritious foods and understanding your appetite. Avoid diets that focus on short-term weight loss, they are very difficult to keep to, and when you stop them you're more likely to put weight on. This is called yo-yo dieting.

A Mediterranean diet pattern with a focus on a variety of foods, increasing fibre content from fruits and vegetables, varying protein sources to include plant based protein such as legumes, nuts, seeds, and including omega 3 fats from fish, can be a good basis for managing many chronic diseases which may occur in people living with lipodema.

Not sleeping well impacts your metabolism and hunger levels. You're more likely to eat higher energy foods and be less active when you sleep badly. Improve sleep by getting into a sleep routine, avoid screens before bed and avoid caffeine in the evenings.

It might seem straightforward that physical activity and healthy eating can help weight management – but in reality, it's much more difficult. Your best weight is the weight you can maintain, while living the healthiest and happiest life that is sustainable and enjoyable for you.



Complementary Therapy

Complementary therapies may help to ease your pain and discomfort.

Compression Garment Tracker

Date	Type of Garment	Class	Company	Size	Colour/Comments

Lipoedema Clinician Contact Details:

Therapist:

Phone:

Email:

Further information

Living Well Programme

<https://hsehealthandwellbeingnews.com/what-is-the-living-well-programme/>

Lipoedema Association Ireland

<https://www.facebook.com/LipoedemaAssociationIreland>

Advice on Physical Activity;

<https://www.who.int/news-room/fact-sheets/detail/physical-activity>

Cross Border Directive

<https://www2.hse.ie/services/schemes-allowances/cross-border-directive/>

Lipoedema Website

<https://lipoedema.co.uk/>

Advice on Weight Management

<https://icpobesity.org/wp-content/uploads/2021/10/HSE-Talking-About-Weight-Guide-final.pdf>

Lipoedema Support Network Ireland

<https://www.lipoedemasupportnetworkireland.ie>

