

Lipoedema Support Metwork Freland Members' Manual





IMPORTANT

Lipoedema Support Network Ireland, is first and foremost a support group for women living in Ireland with lipoedema. It was created by AnnMarie McGoldrick in 2023, and is supported by volunteers. Our goal is not only to support women but to help raise awareness of lipoedema in Ireland, and beyond. We strive to do this without compromising our members and their privacy.

This manual has been prepared for and by members that have volunteered their time. It is based on personal experiences and recommendations of all our members. Its purpose is to act as a guide to help members through their lipoedema journey. If you have any questions relating to this manual, please contact one of the admin team, which can be found on WhatsApp.

Admin have no affiliation with any names (except for their own personal journey), nor do they take responsibility for any recommendations. We have built a trusted list of resources for you throughout this manual, however, we strongly recommend members supplement this with their own research.





WHERE TO START

If you think you have lipoedema or are newly diagnosed, it can be overwhelming. The important thing is to know that you are not alone and there are many women on this same journey as you. Don't be afraid to ask questions as we were all new at one point, and would not have been able to do it without the support of those before us. Use this manual and the community as your support network to navigate your lipoedema journey.

Take your time to process it all and remember, you don't need to do everything at once. Identify what is your first priority e.g. getting an official diagnosis, and take it one day at a time \heartsuit







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Section 1 Getting a Diagnosis in Ireland





TYPE OF DIAGNOSIS

Medical diagnosis is a diagnosis provided by a medical doctor who undertakes diagnostic tests to confirm the diagnosis.

Although there is no diagnostic test to diagnose lipoedema, doctors can use diagnostic testing to rule out other illnesses such as venous insufficiencies, before giving a diagnosis of lipoedema.

Clinical diagnosis is made based on medical signs, reported symptoms, and medical history, rather than diagnostic tests.

If travelling abroad for surgery, some surgeons (primarily German surgeons for VAT purposes) require a medical diagnosis.







HOW TO GET DIAGNOSED

Medical Diagnosis

- Caitríona Canning Vascular Consultant, Dublin (Public St. James Hospital | Private - Hermitage Clinic)
- Julie Reed Vascular Consultant, Belfast (Public Belfast Health and Social Care Trust | Private Kingsbridge Private Hospital)
- Donegal HSE Primary Care Letterkenny
- Meath HSE Primary Care Summerhill
- Clare HSE Primary Care Ennis

(HSE primary care clinics are only applicable if you live in those counties)

- Your GP
- Lipoedema specialist surgeons Irish based such as Plastic Surgeon Dr. Deirdre Jones

Clinical Diagnosis

- Physiotherapists
- Some MLD therapists see section 5 for MLD therapists that provide a diagnosis
- Lipoedema specialist surgeons foreign surgeons (if done virtually)



Section 2 Information for Medical Professionals





WHAT IS LIPOEDEMA

Lipoedema is a connective tissue and adipose tissue disorder that predominantly affects females. Lipoedema is typically present in the lower extremities but can be present in the upper extremities, especially the upper arms.

Research indicates that it may be hereditary and may be triggered by hormonal changes in the body; puberty, birth control, stress, pregnancy, fertility treatments, and menopause.

Current findings suggest that lipoedema is a progressive disease, so early intervention is critical to avoid mobility restrictions, inflammation, fibrosis, pain, secondary obesity, lymphedema, and high volume (higher risk) liposuction.

Here is a link to the <u>HSE's Model of Care Plan</u> & see section 11 for research papers that can also be shared.





SYMPTOMS & SIGNS OF LIPOEDEMA



Not all patients present the same way. Some women will present with all of the symptoms, while others may only have one or two. Recent guidelines no longer recommend using a staging system. We have included it as some German surgeons still require it in the official diagnosis for VAT purposes.

This is not an exhaustive list but includes the most common symptoms.

- Ankle and/or elbow cuffs
- Weight not responsive to diet or exercise
- Family history can be direct maternal line or from females on the paternal side
- Swelling on both legs
- Disproportionate lower body with slim waist
- Heavy arms and legs
- Bruise easily
- No swelling on hands or feet
- Legs and arms are sore to touch
- No visible knee caps and/or fat pads around knees
- 'C' curve on thighs
- Cellulite-like skin dimpling



LIPOEDEMA VS OBESITY

LIPOEDEMA

Affected areas can be painful & tender, bruise easily

Unresponsive to conventional diet & exercise

Doesn't typically have obesity related health issues

Does not tend to involve feet or hands

Often occurs with hormonal changes

Predominantly female

Vs

Vs

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VS

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VS

OBESITY

No pain, tenderness or bruising

Responsive to conventional diet & exercise

Can have health issues such as diabetes & heart issues

Affects the whole body

Can develop from early childhood

Male & female





LIPOEDEMA VS LYMPHEDEMA

LIPOEDEMA

Bilateral & symmetrical

Non-pitting

Does not tend to involve feet or hands

Infections & open wounds are rare

Predominantly female

Vs

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LYMPHEDEMA

Tends to be one limb only if cancer related, whereas all others can be bilateral

Pitting edema occurs in early lymphedema

Can be apparent in feet & hands

Infections & open wounds are common

Male & female







Section 3 Compression Garments





COMPRESSION - ALL YOU NEED TO KNOW

Custom Brands

- Jobst
- Medi
- Bioflect
- Marena
 - Juzo
- Czsalus
- Lipoelastic

Off-the-Shelf Brands

- Czsalus (24IRL5 5% discount)
- Lipoelastic (lipogarments 15% discount)
 - Marena
 - Solidea

Where to get Measured

- Serranova
 - HC21
- Some MLD therapists (see section 5)

Medical Card Holders

Medical card holders are entitled to 2 pairs of compression a year. Contact your GP or Public Health Nurse for more information.



Section 4
Nutrition





NUTRITION INTRO

Thank you to Virginia Ziulu, who has kindly put together the following information and advice on nutrition for lipoedema. Virginia is a Nutritional Therapist (AdvDipNT mNTOI) and specialises in lipoedema nutrition.

I am passionate about helping
Lipoedema patients to have a better
quality of life, reducing pain and
swelling but most importantly have
a better relationship with their
own body.



Lipoedema patients have been shown to be more prone to insulin resistance and carbohydrate sensitivity. Low carbohydrate regimes are particularly beneficial for Lipedema patients to control swelling and pain. The most problematic carbohydrates are simple sugars, starches and processed grains which can drive inflammation.





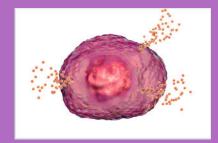


HISTAMINE & MAST CELLS

Histamine is the biggest inflammatory chemical in the body and it comes from immune cells called Mast Cells. It gets released and triggered by many factors including food, heat and sun exposure, estrogens, medications, exercise, alcohol, and much more. It is vital to assess Histamine issues in every lipoedema patient and this can be done with the support of a Nutritional Therapist or Dietician. A low Histamine diet can be an option to understand the root causes of histamine issues.

Lipoedema is linked with Histamine and Mast Cell problems.











DETOXIFICATION PROCESS

In lipedoema, the detoxification process happens much more slower due to genetic components and mechanical issues, due to the pressure on the lymphatic system to eliminate all the waste material. The main organ involved in detoxification is the liver which filters everything from chemicals, medications, hormones, and it does this with a group of enzymes called CYP enzymes, and a process called Methylation. Lipoedema patients have been shown to have genetic mutations in these genes which can compromise how well the liver processes these hormones and chemicals.



This in turn can cause a worsened inflammatory response as the body is working hard to remove these waste products. It is therefore vital to consume a diet rich in antioxidants to help the liver in these processes. If you think of colours, that's where you will find all the beneficial antioxidants. Each colour has a different antioxidant, to protect and improve the function of each cell in the body. Green Tea is a very beneficial tea to support hormonal balance as well as Tulsi (Holy Basil) which also supports hormonal balance.





ANTI INFLAMMATORY FOODS

1. Healthy Fats

Olive oil, walnuts, avocados, grass-fed butter and coconut oil.

Healthy fats contain fat soluble vitamins like Vitamin E and A which are very powerful anti-oxidants and can help to reduce inflammation.

2. Turmeric

Turmeric is a very powerful spice that has very high antiinflammatory proprieties. It can be consumed in foods or taken as a supplement. It is also a vasodilator and vasoconstrictor. It gets activated with a pinch of black pepper.

3. Organic Foods

Organic fruits and vegetables which are pesticides free and chemical free. In particular berries and leafy greens.

The peel of fruit and vegetables is the highest in antioxidants.

Lemon and orange peel have particularly high levels.







MULTIDISCIPLINARY APPROACH

It is so important to have a multidisciplinary approach for lipoedema patients. From nutrition to lifestyle managment to exercise, and have a team of lipoedema experts around you.

Educate other healthcare professionals about lipoedema but also make sure they have a genuine interest and knowledge in the condition. Request their qualifications and background, and don't be afraid to ask questions.











Section 5 MLD Recommendations





MLD IRELAND

MLD Ireland

MLD Ireland is the professional Organisation of Health Care Practitioners, who have obtained additional and specialised training to provide treatment in the management of the lymphatic system. MLD helps to relieve symptoms, but some members have also tried other circulation boosting massages and found them just as beneficial.

If there are no MLD therapists listed below for your area, we recommend checking out the <u>MLD Ireland website</u>. Therapists listed under the 'Advanced' section should have experience with lipoedema.

About MLD Therapists

The primary job of a MLD therapist is to perform manual lymphatic drainage or decongestive lymphatic therapy. Some therapists also provide clinical diagnosis for lipoedema as well as measure for custom made compression garments.

The therapists listed below are therapists used by our members. It is not an exhaustive list of therapists operating in Ireland. In some cases, the therapist is a physiotherapist, who are also recognised to perform MLD for lipoedema.

MLD THERAPISTS

Leinster

Fiona Crilly Mitchel - Dublin**
Tania King - Wicklow
Siobhán Casey - Louth* (also Northern Ireland)
Daniela Palazzi - Kildare
Alan O'Sullivan - Dublin
Mary Shelly - Kildare
Deirdre Cullivan - Dublin*
Bernadette Traynor - Dublin **
Theresa Allen - Laois

Munster

Darren Prince - Cork
Anna Mottha - Cork
Meadbh McSweeney - Cork*^
Monica Conway - Tipperary*
Maria Kirby - Cork
Finola Craven - Cork
Karen O'Sullivan - Limerick
Anne O'Connor - Clare

Connacht

Mary Ellen Flaherty - Galway Elaine Grehan - Galway

*Clinical Diagnosis

^ Measures for Compression



Section 6 All Things Surgery





GETTING STARTED

- Do your research.
- Make sure you understand the treatment, potential risks, & what is involved with recovery.
- Chose a shortlist of at least 3 surgeons based on your top requirements.
- Join lipoedema surgical Facebook groups and check if the surgeons have patient Facebook groups.
- Ask in our surgery subgroup if anyone has had surgery with your chosen surgeons.
- Pick a surgeon that specialises in lipoedema and has a history of treating lipoedema patients.
- Ideally you want a surgeon that treats patients with a similar stage and medical history.
- Have consultations with at least 3 surgeons although some of our members knew after one consultation that they had found their surgeon....trust your gut!
- Check your shortlisted surgeons' credentials and if they have had restrictions imposed.
- Don't feel rushed, and take your time.
- Make sure you talk to some of their current patients. We have found women quite open to helping others so don't be afraid to reach out to individual people within our own community or online.





THINGS TO CONSIDER WHEN CHOOSING YOUR SURGEON

- Their medical training, lipoedema training, and that they're a registered medical profession.
- Any patient and peer endorsement.
- Are they known for their 1-1 attention and communication.
- Ask them about their complication rates.
- How many surgeries do they perform daily/weekly.
- Does the surgeon participate in scientific research relating to lipoedema.
- That they consider aesthetics as well, if this is important to you.
- Do they have skin tightening facilities.
- That they have strong English speaking ability.
- The surgeon is a plastic surgeon so they can perform skin removal, if that is something you feel you will need.
- Have they experience dealing with any secondary health issues you may have e.g. lymphoedema, heart issues, cancer recovery.
- Does the surgeon have BMI limits?
- Ask to see their before and after portfolio. They should be able to share this privately with you, if it's not publicly available on their social media/website.





THINGS TO CONSIDER RELATING TO SURGERY

- What is included in the cost of the surgery, and what is potentially additional.
- Is the surgeon able to do all areas that require treatment.
- What surgical method do they use? The 2 common methods are WAI & PAL. Some surgeons use Vaser as an additional to either WAL or PAL. Vaser is used to soften the fat before extracting it, using either WAL or PAL. The most important thing is the skill of your surgeon and their experience with lipoedema. The method doesn't necessarily matter after that, but some women do have preferences.
- Does your surgeon leave the wounds open or closed? Open wounds will involve leaking which requires additional preparation. It is said to lead to quicker healing time but every patient heals differently, regardless of method used.
- What is their surgical approach for you, and the number of surgeries required.
- Do they use general or local anaesthesia.
- What is the max litres of fat removed. In Ireland and UK, this tends to be maxed at 5L but in the EU, surgeons can go up to 10% of body weight.
- The expected length of your surgery.
- Length of time between each surgery.
- Is the hospital of good standard and have good reviews does the surgeon work for the hospital or rent the OR.
- Would you prefer shorter or longer stay in hospital.

THINGS TO CONSIDER POST-OP

- The length of stay in the country, the surgeon requires post discharge.
- Visiting hours, if you have people travelling with you.
- Preference for private or shared room.
- Ability to stay longer in hospital, if medically required.



- If post-op MLD is included in the surgery price, easily available, and the additional cost if not included in price.
- Post-op care and availability.
- Ability to provide prescriptions post-op.
- Willingness to liase with your healthcare providers at home, if necessary.
- Willingness to complete health insurance or CBD documents.





SURGEONS

- Dr. Mojtaba Ghods Germany
- Dr. Jafar Jorjani Germany
- Dr. Kai Klasmeyer Germany
- Dr. Lissa Masumbuku (Medplast) Germany
- Dr. Birgit Jungehulsing (Medplast) Germany
- Dr. Christina Kunkel (Lipoclinic) Germany
- Dr. Marion Heck (Lipoclinic) Germany
- Dr. Johanna Schreiber Germany
- Dr. Iakovos Georgiou Cyprus
- Dr. Enrique Burgos de la Obra (Lipemedical) Spain
- Dr. Garcia Reyes (Lipemedical) Spain
- Dr. Barquin (Lipemedical) Spain
- Dr. Acosta (Lipemedical) Spain
- Dr. Hernandez (Lipemedical) Spain
- Dr. Petr Šíma (Aestea) Czech Republic
- Dr. Apostolos Siafliakis Greece
- Dr. Agnieszka Czarnecka Poland
- Venus Medical Dublin
- Auralia Clinic Dublin

*These are just some of the surgeons used by our members.

PACKING LIST

- At least 2 pairs of compression garments and compression glider
- Sheewee and side tie bikini, if using crotchless compression
- Supplements such as iron (easy iron or liquid form is best for the stomach) and magnesium
- Electrolytes and jelly babies for energy levels
- Puppy pads, water wipes, gauze, and micropore tape (if your wounds are not stitched)
- Old clothes and cheap flip flops (if not stitched)
- Loose or adjustable shoes such as Crocs, in case of swelling on the feet
- Antiseptic cream, arnica, Senokot
- Antihistamines in case of reaction to the anaestetic
- Ear plugs and eye mask
- Long charging cables as plugs can sometimes be out of reach in hospitals
- Plug adaptors
- Electronics and books for entertainment
- CBD forms for surgeon to complete (these can also be emailed in advance)
- Notebook and pen to take notes from your surgeon, and a folder for all important documentation
- Padlock or other for suitcase in case of no safe in the room
- Gifts for surgeon and nursing staff (optional!)



POST-OP CARE AT HOME

- Follow all advice and guidance from your surgeon. The tips below are a guide based on our members' experience.
- Make sure you have post-op MLD booked ahead of time. The frequency can be dependant on your budget. Ideally at least 2 times a week for the first few weeks and then upon guidance of your MLD therapist.
- Light and regular movement is important to help with swelling.
- Typically from week 3 you can increase intensity, with intense exercise from week 6.
- Use antiseptic cream on your wounds and when fully healed, use scar oil or silicone tape. Make sure to massage the wounds to break down any fibrotic tissue and hardness.
- Wear compression for at least 6 weeks, and more if required, for swelling and to help with skin retraction (or otherwise as instructed by your surgeon).
- Compression pumps can be typically used once wounds are healed.
- Keep an eye out for any infections or redness. If you notice any, feel unwell or have a temperature, contact your GP and surgeon straight away. In case of emergency, go straight to hospital.
- Seromas are common post surgery. Let your surgeon know and follow their advice. Typically they can be treated by compression and MLD. In cases where they are large or hard, they may need to be drained. It can take time for them to disperse naturally.







Section 7 Cross Border Directive

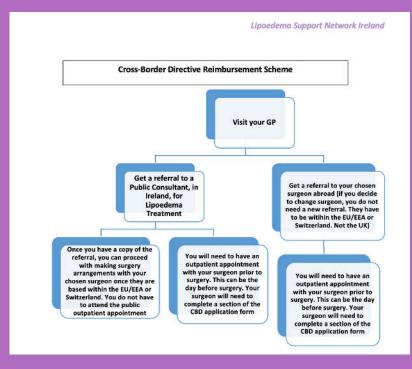




CBD INTRO

The Cross Border Directive is a HSE and EU Commission scheme, that allows Irish patients to access healthcare in another EU state.

For treatment to be eligible, the treatment must have been performed within the public health system in Ireland. There is one known case where liposuction for lipoedema was performed within the HSE, and this has allowed Irish women to now seek treatment abroad funded by the CBD.



CBD PROCESS

1. GP Referral Letter

To either your chosen surgeon within the EU/EEA or a public consultant in Ireland. You do not need to attend the public consultant appointment.

The referral letter must be dated before your outpatient appointment and surgery. (See section 11 for example letter).



2. Prior-Notification

Prior-notification may be sought but is not required. This is not a guarantee of reimbursement, nor will any reimbursement amount be confirmed. It is confirmation that you have followed the public patient pathways and will be eligible for reimbursement. Prior-notification cannot be issued unless you have had an outpatient appointment with your surgeon. If you have received reimbursement for your first surgery, any subsequent surgery under that surgical plan will be considered a follow on and therefore you do not need to apply for prior notification. Follow on surgeries are eligible for reimbursement and do not require a separate referral letter but a separate reimbursement form must be submitted.

3. Outpatient Appointment

This can be attended either the day before or the day of your surgery. The outpatient appointment for your first surgery is sufficient for all subsequent surgeries.

CBD PROCESS CTD.

4. Complete Forms

Your surgeon will be required to complete Section B and sign off on the form.

When completing the Pro-Forma Invoice form for your first surgery, you can also get your surgeon to complete the prenotification forms for any further surgery. Forms do not need to be the original and your surgeon can email them to you.

5. Supporting Documents

Along with the forms you will require the following:

- Proof of travel flight ticket & hotel receipt
- Discharge letter should state date & time discharged
- Patient report if patient notes are not included within the discharge letter.
- Invoice showing full breakdown of costs. If your surgeon provides transport or compression garments, these are not reimbursable. To avoid delays with your application, they should be separated out on the invoice. Only costs relating to the actual surgery are allowable.
- Proof of payment shown on your bank statement which should include your name & address. If a family member paid on your behalf, this should be clarified when submitting.
- Proof of outpatient appointment.

All documentation must be in English. Any documentation in a different language must be translated.

CBD PROCESS CTD.

6. Outpatient Reimbursement

This is treated separately from the reimbursement for the surgery. Proof of your appointment should be included with supporting documentation. If you paid for the outpatient appointment, reimbursement is available up to €194. Proof of payment should also be included. Make sure this is not included in the surgery amount on the main CBD forms.



7. Send Application

We would recommend sending by registered post. Processing times are approx. 6 weeks and could be longer if further information is required.

An approval letter is issued with payment sent after, typically in the form of a bank cheque. Payment can take between 2-4 weeks to receive but members have received it within a few days of receiving the approval letter.

1. DRG codes explained

The DRG code is set by the HSE and not determined by the CBD office. There is currently no set DRG code for lipoedema treatment. To verify the code, the CBD inputs each patient's details into the system and an algorithm will determine if the code is correct based on the patient's medical history, treatment received, and demographics. This means members can receive reimbursement under different codes depending on medical history, stage, hospital stay etc. We have not yet seen a scenario where members have been reimbursed differently from others.

2. What DRG code to use?

Members to date have received reimbursement under Z01B, which reimburses the lower of your surgery cost or €10,252 (based on the new 2024 list for surgeries from 1st July 2024. Pre July 2024, it is maxed at €6,434).

Members have submitted applications under the Z01A code but to date, they have been reviewed and approved under the Z01B code. This is currently under review and if there is any change to the situation, we will update our members.

3. Is skin tightening covered?

Skin tightening (Bodytite, Renuvion, J-plasma etc.) may be reimbursed if it is indicated by your surgeon to be medically necessary.

Potential medical reasons include:

- The heating effect of the laser causes a reduction of bleeding which leads to fewer circulatory complications and faster healing time.
- The tightening also ensures tightening of the connective tissue which can help avoid otherwise necessary tightening operations and avoiding putting the patient under further anaesthetic.

4. Are skin removal/lifts covered?

As of yet, we have not had any member submit for skin removal. If you are financially reliant on the CBD, we would strongly recommend seeking prior-notification for your skin removal surgery. It is important that the skin removal is stipulated as part of your lipoedema treatment and the medical necessity is stated by your surgeon. Examples of medical necessity include causing irritation, affecting mobility, risk of infection, and impacting walking and posture.

- 5. Can I get prior-notification before my first surgery? Prior-notification will only be issued if you have had an outpatient appointment in person, with your surgeon. Proof of appointment and flights will be required.
- 6. How long does prior-notification last for? Prior-notification does not expire until you have your surgery.
- 7. Do we have a direct point of contact? Yes, Catherine Donohoe (catherineT.donohoe@hse.ie). Catherine may be contacted if you have any questions on how the scheme works or would like to ask something specific to your scenario. We would recommend asking in the CBD WhatsApp group first. If you have questions relating to your application, it is best to ring the CBD office on 0567784546 as you will be directed to the team member looking after your application.
- 8. How long does it take for the reimbursement to be processed? Typically it takes 6 weeks from submitting the application to receiving approval letter. Payment is processed by cheque which is issued separately and can take up to 4 weeks to be issued (members have received within a few days).

If there are any queries or additional documentation is requested, this will delay processing.

9. Can I appeal the decision?

Yes, internal reviews can be requested within 3 months of the date of your decision letter. Requests for a review can be directed to:

Frances McNamara,
Assistant National Director,
National Schemes & Reimbursement
Dr. Steeven's Hospital,
Steeven's Lane,
Dublin 8,
D08 W2A8.
01-2408769
scheme.queries@hse.ie

10. I'm still not happy, can I appeal further?

Complaints can be made to the Office of the Ombudsman, which is independent from the HSE and CBD. This is a free process and can be done through one of:

- Through their website, here.
- By letter
- By phone

11. Do I need to submit an application for each surgery?

Yes, a reimbursement form is required for each surgery. However, you do not need a new referral letter for each application as your original letter is kept on file from your first application.

12. Is CBD open to Northern Ireland residents? Unfortunately not at this moment. NI women should consider applying for PIP. There have been UK women, who work, that have been successful in achieving PIP status for lipoedema. They have used this funding to pay for their surgeries.

- 13. Does my application have to be the original signed version? No, scanned copies sent from your surgeon are acceptable.
- 14. Can I apply for the Treatment Abroad Scheme (TAS)? No, unfortunately TAS is not available yet for lipoedema surgery.
- 15. What are GPs' obligations regarding referrals? GPs are not required to refer you to a surgeon abroad. However, they should refer you to a public consultant in Ireland, which is sufficient for CBD purposes.
- 16. What are GPs' obligations regarding post-op surgery care? GPs have a medical responsibility to treat you regardless of where you had surgery. To not treat you would be considered medical neglect.
 - 17. If my private health insurance covers part of my surgery cost, can I claim the balance under CBD?

No, this would deem you ineligible for CBD. The full cost must be claimed for under CBD. You can claim if you were rejected by your health insurance, as long as you have met all the above criteria.

18. If I have private health insurance but I don't claim for surgery costs, can I still apply for CBD?

Yes, but leave the private health insurance boxes blank.

19. If my GP has referred me to a surgeon but I subsequently change surgeons, do I need a new referral letter?

No, you can change surgeons at your own discretion.

20. If I have already paid for surgery out of my own pocket, can I submit a subsequent claim for CBD?

Yes, we have known members to submit back as far as 2022. However, this is at the discretion of the CBD office so may be on a case by case basis. You still are required to have followed the above process and have all relevant documentation.

- 21. Can I get reimbursement for travel and other expenses? No, travel costs are not included. Only the surgery costs are included.
- 22. How many people have been reimbursed for lipoedema surgery, to date? And, has anyone been rejected? As of July 2024, 8 members have successfully been reimbursed with some having received more than one reimbursement. We are not aware of anyone being rejected.

23. If I am getting a lower volume surgery, will I be reimbursed less than the amount indicated?

You will be reimbursed the lower of the amount assigned to the DRG code and the cost of your surgery. It is not impacted by volume or body parts operated.

24. Do I need to be on a waiting list in Ireland to be eligible for CBD?

No. Once you have a valid GP referral letter, that is you deemed to be on a public waiting list.

- 25. I was diagnosed by a private consultant, can I use this for CBD? No, you will be required to get a public path referral from your GP.
- 26. If my GP referral letter is addressed directly to my surgeon abroad, is that considered to be the public pathway? Yes, nothing further is required.
- 27. If I claimed for my first surgery under private healthcare, can I claim for subsequent surgeries under CBD?

 Yes, as long as you have followed the above process.



Section 8
Insurance





INSURANCE FAQ

How to choose a health insurance policy?

You will require a policy that includes "elective overseas treatment" as a benefit. Some insurers have declined applications because this particular benefit isn't on the policy. If you have a policy without this benefit, you may be able to argue that the procedure isn't available here in Ireland, and therefore forcing you to go abroad. We have yet to hear of a successful case winning this argument.

What are waiting periods?

A waiting period is the length of time you need to have health insurance before you can make a claim. Typically, as a new customer to health insurance in Ireland, a waiting period of 5 years will apply for a pre-existing condition.

How does health insurance know about pre-existing conditions? "Pre-existing condition" means an ailment, illness or condition, where, on the basis of medical advice, the signs or symptoms of that ailment, illness or condition existed at any time in the period of 6 months ending on the day on which the person became insured under the contract.

When should I apply to my health insurer for surgery? Generally, insurers require that you apply to them within 6 months of your surgery date. Once approved, the approval will be valid for 6 months.



Section 9 Health Expenses Tax Refund





CLAIMING FOR HEALTH EXPENSES

How much?

20% of the costs (based on standard tax rate). If you have been reimbursed under the Cross Border Directive or from your health insurance, you can only claim 20% on the balance not reimbursed.

Relief is granted by way of a tax refund so you must have paid tax in the relevant year.

What is covered?

- Surgery cost
- Compression garments
- Manual lymphatic drainage
- Consultation fees
- Blood and diagnostic tests
- If travelling for surgery, reasonable accommodation and travel costs for you and a person that travels with you.
- Prescription costs
- Compression pumps or other appliances where they have been advised by a medical practitioner.
- Other costs not included but have been recommended by medical professionals.

CLAIMING FOR HEALTH EXPENSES

How can I claim?

You can claim online through your Revenue myAccount. If you don't have one, you can set one up here, You must have valid receipts for all expenses.

You must complete for each individual tax year, and can claim for the last 4 years. You can now claim throughout the tax year and do not have to wait until January.

Cosmetic treatments are not eligible so you may be asked to provide evidence of diagnosis or a GP referral letter.



*Section 10*Conservative Measures





COMPRESSION GARMENTS

Compression garments will not remove lipoedema from affected areas but can help with managing symptoms. They can help improve circulation and support the lymphatic system.

Key benefits of compression are

- Reduction of discomfort and heaviness
- Support the tissue and limbs
- Reduce swelling in cases of fluid retention
- Improve mobility

Custom made compression garments can be expensive and are not currently covered by health insurance. Medical card holders are able to get 2 free pairs a year. See section 3 for more info on compression brands.





LIPOEDEMA FRIENDLY DIET

See section 4 for detailed information on nutrition for lipoedema.

What are the benefits of a lipoedema friendly diet for conservative management? An anti-inflammatory diet can help reduce or remove pain and swelling.

Following a lipoedema friendly diet, promotes a healthy way of eating. This will lead to better mental and physical health. It can also help minimise non-lipoedema weight gain which can help prevent further progression of lipoedema.



While there is no universal diet for lipoedema, the general consensus is:

- Reduce inflammatory foods
- Follow a mediterranean style of eating
- Reduce simple sugars, starches, and processed grains
- Limit alcohol
- Reduce dairy
- Eat fresh foods and where possible, organic foods



STRESS MANAGEMENT

When a person experiences stress, the body will release stress hormones including cortisol, to help you respond and adapt to the stress. Cortisol is an anti-inflammatory hormone. If you experience chronic stress, your cortisol levels will decrease leading to increased inflammation and swelling.

Stress can also have negative impacts on sleep and eating habits.



Ways to help manage stress:

- Fresh air for at least 30 minutes a day
- 7/8 hours sleep a night if you struggle to sleep try tools like white noise or no devices the hour before bed.
- Exercising
- Surround yourself with family and friends that have a positive influence.
- Spa or treat days for yourself
- Reading
- Yoga, meditation or breathing sessions

EXERCISING

A lot of women with lipoedema struggle with mobility. This can impact their ability to do basic exercise such as walking. Wearing compression garments while exercising can make exercising more comfortable and help keep the fluid from building up.

This can be one of the primary factors women with lipoedema can suffer from a comorbidity of obesity.

If you struggle with pain and mobility, it is advisable to do low impact exercises with a focus on building your overall body strength. Here are some recommended activities:

- Strength training to build muscle
- Aqua aerobics
- Swimming
- Walking
- Yoga
- Pilates
- Rebounding





HEALTHY LYMPHATIC SYSTEM

The lymphatic system is responsible for fluid movement throughout the body, and it helps remove waste and toxins from the body. When the lymphatics do not function properly, this can lead to a build up of fluid, and cause swelling and inflammation. This is experienced by many women with lipoedema as both lipoedema and non-lipoedema fat causes additional pressure on the lymphatic system.

By having a healthy lymphatic system, it reduces the pressure on the limbs and it leads to healthier tissue and fat cells.



These are just some things that can help maintain a healthy lymphatic system:

- Exercising
- MLD
- Compression pumps
- Dry brushing
- Vibration plates
- Kinesio taping
- Compression garments





REDUCE FIBROSIS

Fibrosis is present in all stages of lipoedema and can be caused by inflammation.

Fibrosis forms around the subcutaneous fat cells, creating nodules. These nodules can become large, lumpy, and painful masses.



As well as the measures mentioned above for the lymphatic system, here are other measures that can be taken to help reduce fibrosis and pain:

- Myofascial release
- Cupping
- Gua Sha
- Deep Oscallation
- Deep tissue massage (note that this can be very painful for lipoedema so may not suit everyone)





Section 11 Useful Links & Resources





USEFUL LINKS

Irish Lipoedema Support Network - Instagram
Irish Support Network - Facebook
HSE Model of Care for Lipoedema
Cross Border Directive Website
CBD Application Form
CBD Prior Notification Form
Surgeon Research - Global Lipoedema Awareness
Lipedema Foundation
The Lymph Clinic Cork

INSTAGRAM ACCOUNTS TO FOLLOW

<u>Virginiashealthcorner</u> - lipoedema nutrition <u>ladyloglegs</u> - lipoedema research <u>lymphloveclub</u> - lymphatic system advocate <u>lipedema_mamas_podcast</u> - all things lipoedema <u>wellnesswarrior.ie</u> - menopause coach <u>benbikmanphd</u> - metabolic scientist <u>lipedema_uplifted</u> - holistic wellness for lipoedema <u>alexlight_ldn</u> - body confidence



RESEARCH

- <u>Lipoedema vs Normal Fat</u> Dr. Karen Herbst
- <u>Lipedema; Pathogenesis, Diagnosis, and Treatment Options</u> Dr. Kruppa, Dr. Georgiou, Dr. Ghods
- <u>Disease progression and comorbidities in lipedema patients: A 10-year retrospective analysis</u> Dr. Kruppa, Dr. Georgiou, Dr. Ghods
- <u>Survey Outcomes of Lipedema Reduction Surgery in the United States</u>
 Dr. Karen Herbst, Dr. Thomas Wright
- <u>Improvements in patients with lipedema 4, 8 and 12 years after liposuction</u> Dr. Axel Baumgartner
- <u>Liposuction in the Treatment of Lipedema: A Longitudinal Study</u> Dr. Mehran Dadras, Dr. Ghods
- <u>Tumescent liposuction in lipoedema yields good long-term results</u> Dr. W. Schmeller
- <u>Water-jet-assisted liposuction for the treatment of lipedema:</u>
 <u>Standardized treatment protocol and results of 63 patients</u> Dr.
 Thomas Witte, Dr. Falk-Christian Heck, Dr. Marion Heck
- <u>Standard of care for lipedema in the United States</u> Dr. Karen Herbst
- <u>Understanding Lipedema & Lymphatic Flow</u> Dr. Thomas Wright
- <u>Lipoedema: a paradigm shift and consensus</u> Tobias Bertsch, Gabriele Erbacher, Rebecca Elwell, Hugo Partsch

SAMPLE REFERRAL LETTER TO SURGEON

Dr. Surgeon's Name Surgeon's Address

Date

Re Patient XXXX

Dear Dr. X

Thank you for seeing the above patient with stage X lipoedema.

X was diagnosed with lipoedema on X/X/XXXX. It is impacting on her quality of life. There does not appear to be any further lifestyle interventions possible and therefore surgery is now deemed a suitable option.

Your opinion and intervention would be very much appreciated.

Yours sincerely, Dr. GP





PRO FORMA INVOICE

APPLICATION FORM FOR REIMBURSEMENT TOWARDS THE COST OF MEDICAL TREATMENT UNDER THE PROVISIONS OF THE CROSS BORDER DIRECTIVE SECTION A- To be completed in full by Patient/Applicant

Patient Details NAME: ADDRESS: Lipoederna Support Network 123 XXXX DATE OF BIRTH: 20/X/XXXX TEL NO: 087000000 MOBILE NO: PPS NO: MEDICAL CARD NO: XXXXXXXXX *Submit Photocopy also Are you in receipt of a pension or other income from another country? If so which other country and please provide details to include the type and value of the income. (Please identify the type of pension. Evidence of the pension will be required) IMPORTANT - Please see pensions note on page 8 for further explanation. Are you a dependent of a person who is in receipt of a pension or other income from another If so which other country and please provide details to include the nature and value of the income. NAME PRIVATE HEALTH MEMBERSHIP NO. INSURANCE COMPANY HAVE YOU APPLIED TO YOUR HEALTH INSURANCE COMPANY FOR FUNDING? IF YES, HAS FUNDING BEEN APPROVED BY YOUR HEALTH INSURANCE COMPANY? Please submit a copy of the decision letter with your application. The details of the referring clinician below are required or you may attach a copy of the referral letter as an alternative Name of Patient's GP GP's Address 123 XXXX GP's Telephone Number Please read in full before signing the declaration. No liability shall attach to the Health Service Executive, its servants or agents in respect of any costs or expenses incurred by the Patient or Applicant on this application and the results of such determination being communicated to the Applicant. Any arrangements made by the Applicant or Patient prior to such determination may not subsequently be ratified by the Health Service Executive and may invalidate the application. In completing this application form, you must ensure the information you provide is accurate and true. The inclusion of false, misleading or inaccurate information or the omission of information relevant to the decision on reimbursement will mean the CBD office will reserve the right to refer the matter to the appropriate authority and the repayment of any reimbursement drawn down will be required without exception. The CBD office reserves the right to review a patient's medical records to clarify any information as appropriate. I accept that in the event of the submission of false, misleading or inaccurate information or documentation or the failure to submit relevant information for the purposes of seeking reimbursement from the HSE, that the claim will be disqualified for any further consideration and that all outstanding costs will be a matter for myself. In submitting this Pro Forma Invoice (complete or incomplete), I the undersigned give my permission for my medical records or other clinical information to be accessed and copied for the purposes of processing this claim by the HSE. I understand and accept my clinical information can and may be provided to other hospitals, healthcare facilities or clinical advisors in the assessment of the reimbursement claim. In signing my name hereunder, I acknowledge and accept this position and give my consent for I declare that the above particulars are true and correct. I am aware that reimbursement is based on the information provided by me and that any additional information coming to light may impact on the monies reimbursed and I will be liable to repay any monies secured by me on the basis of incorrect, misleading or omission of information. I also agree to notify and arrange to refund the HSE immediately should I receive any refund from the provider or any other party eg insurance provider in respect of the treatments for which the costs were reimbursed to me by the HSE. Such reimbursement will be due to the HSE without delay and in the case of undue delay, I understand that the HSE may seek interest on monies due. 282 20/X/XXXX Applicant's signature Date

3

Parent/Guardian Details Only complete the next sect	ion if you are making an application	on behalf of a patient under 18 years	s of age or over 18 years of age and dependant.
RELATIONSHIP TO PATIENT:		ADDRESS:	
NAME:			
TEL NO:		MOBILE NO:	
NAME PRIVATE HEALTH INSURANCE COMPANY		MEMBERSHIP NO.	
HAVE YOU APPLIED TO Y	OUR HEALTH INSURANCE COMP	ANY FOR FUNDING?	
	EN APPROVED BY YOUR HEALTH decision letter with your application		
ws and policies and that the		vention. In signing this application fo	ed are fully compliant with their local child protection, you are confirming that you are satisfied the
Signature of Parent or Gu	ardian:		Date:
	pad traffic incident or other accident sation against a third party? etails of your solicitor:	al injury? Yes No	
Solicitors Name (acting for	the patient)		
Solicitors Address			
	aim the cost of treatment received or		and traffic accidents or other accidental injuries are SE Cross Border Directive, resulting from the road
		ke sure that the treatment costs prov tht to the attention of the HSE Cross	ided by the HSE under the Cross Border Directive Border Directive.
I agree to repay to the HSE	the gross amount of the money spe	nt by the HSE when the claim I am p	oursuing against a third party has been finalised.
Applicant's Signature	:	Date:	
_	re the patient has been a victim of a		

SECTION B - (to be completed in full by the treating clinician abroad)

The treating clinician should fully complete Section B and provide sufficient information including details of the treatment provided to the patient. Reimbursement of healthcare is based on the evidence of the medical necessity evidenced in the documentation.

Applications for reimbursement must be accompanied by a copy of the detailed clinical referral letter from the referring clinician to the accepting clinician cutlining details and history of the patient's condition and the type of treatment envisaged. In the case of a reimbursement for inpatient or day case treatment, evidence of the outpatient consultation which took place on a date prior to the inpatient or day case procedure and at which the medical necessity was determined must also be included for the purposes of reimbursement.

The onus is on the treating/referring consultant to seek, provide and certify the answer to each question in Section B.

reame of clinician			SE.				
Name of clinician		Surgeon's name					
Clinician's address/Hospital Address		Hospital name & address where you are having surgery					
Contact details -	telephone, fax and email	Surgeon's cor	ntact details				
	ssional registration details – and registration number	Surgeon's m	edical body registration number				
Patient Name	Lipoedema Support Netw	ork	Patient Address	123 XXXX	<		
Date of Birth	20/X/XXXX			0			
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SECTION B-Continued Please set out hereunder a summary of the condition from which the patient suffers: The patient suffers from lipoedema, stage X, of the lower and upper extremities (if applicable to you), a chronic, progressive, and painful Please identify the specific treatment provided: Since the patient did not have sufficient symptom reduction with conservative therapy for over 6 months, a large volume, functional liposuction of the lower legs was performed. Is this treatment available within the State? YES X (only treatments which are available in or are publicly funded in Ireland qualify for reimbursement under the CBD) Please confirm the reason for accessing the healthcare abroad? (this information has no bearing on the application decision it is recorded for the purposes of information on the reasons why patients are opting for care under the CBD) Length of wait for the treatment in Ireland: X X Quality of the service abroad: Proximity to my place of residence: If Other please provide details: Is the patient currently receiving this treatment in Ireland? YES NO X If yes, please provide details: is the treatment medically necessary? Will the treatment meet the patient's needs? Is this treatment contrary to the Irish Constitution or any legislation to your knowledge? No x Is the treatment regarded as a proven form of medical attention and not experimental or test treatment? Is the treatment required as a result of injuries received in a road traffic accident or other accidental injury? No x Yes Does the proposed healthcare pose any public health risks for the patient and/or the public in general? No X If yes, please give details: 6

SECTION B-Continued											
is the treatment abroad being provided in a recognize Registered Medical Practitioner?	Yes	x	No								
is that hospital a public hospital available to National	Yes	х	No								
THE ONGOING CARE OF A PATIENT WHO HAS AVAILED OF TREATMENT ABROAD REVERTS TO THE REFERRING PHYSICIAN IMMEDIATELY UPON THE PATIENT'S RETURN TO IRELAND.											
I declare that the above particulars are to the best of my knowledge true and correct.											
Signature of treating clinician:	Signed by your surgeon	Date:									
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