From Lipedema to Lipalgia Syndrome

Why we are renaming the condition – and what this means for patients, physicians and therapists

An Overdue Decision

We at the Földi Clinic are changing the name of the condition. What has been called "lipedema" at our clinic until now will be referred to as **lipalgia syndrome (formerly lipedema)**.

This is not a cosmetic change or an exercise in semantics. It reflects what scientific research in recent years has shown and what we observe every day at the Földi Clinic, both in our outpatient clinic and on our inpatient wards.

The name of a medical condition creates expectations, and inaccurate expectations can lead to inappropriate treatment. In our view, this is precisely what has happened in the diagnosis and treatment of "lipedema" for decades.

What the Old Name Implies – and Why That Matters

The word "lipedema" contains the word "edema." Edema means excess fluid in the tissue. When people hear the term "lipedema," it is therefore understandable that they assume fluid is accumulating in the legs and needs to be removed.

In lipalgia syndrome, that assumption is not supported by the evidence.

In the absence of other comorbid causes, there is **no edema** and **no lymphatic dysfunction** in lipalgia syndrome. The lymphatic vessels are **intact**. The German S2k guideline states this clearly in Chapter 4:

> *"Lipoedema is neither an oedema nor a disease manifestation with venous or lymphatic dysfunction."*

The international consensus document, “Lipoedema: a paradigm shift and consensus” (2020), reaches the same conclusion:

> *“Lipoedema neither includes any relevant oedema nor impairs the lymphatic system.”*

That consensus document already reached the conclusion we are acting on now: the term “lipedema” is outdated and should be reconsidered. It was also in that document that the term “lipalgia syndrome” was first proposed.

The late Professor Hugo Partsch, a leading figure in phlebology, wrote in the foreword to that document that *“lipoedema neither includes oedema nor is there any scientific evidence for lymphatic insufficiency.”* He therefore considered decongestive lymphatic therapy an inadequate treatment for patients with pure lipedema.

The evidence has continued to grow. Imaging, histology, molecular biology and impedance measurements have independently contributed to the same overall conclusion – here in the words of the authors themselves:

> ***Hirsch et al. (2018)*** *(high-resolution ultrasound, multicenter registry study): No fluid accumulation could be demonstrated in patients with “painful lipohypertrophy.” The authors conclude that “the disease designation lipoedema is misleading and should be reconsidered.”*

> ***Cellina et al. (2020)*** *(MR lymphography): The fat tissue was homogeneous, “without any signs of edema in pure lipedema patients.”*

> ***Felmerer et al. (2020)*** *(histology and molecular biology, Scientific Reports): The authors found that “no apparent lymphatic anomaly underlies lipedema,” supporting their conclusion that this is a different disease from lymphedema.*

> ***Mackie et al. (2023)*** *(indocyanine green lymphography, ALERT Centre, Sydney): In 40 women with lipedema, an entirely normal lymphatic system was found in 34 participants. In the remaining six women, the findings were not attributable to lipalgia syndrome: four had a localized post-traumatic change at the ankle, and one had previously diagnosed primary lymphedema. The authors concluded that there was an “absence of lymphoedema in a clear majority of women with lower limb lipoedema.”*

> ***von Atzigen et al. (2023)*** *(comparative histology, University of Zurich): Neither the number nor the size of lymphatic vessels in participants diagnosed with lipedema differed from control tissue. The authors regard the "absence of lymphatic vascular alterations in lipedema" as confirmed.*

The International Lipoedema Association (ILA), an international professional organization devoted to this condition, likewise identifies the assumption that lipedema is an edema as a myth in its campaign against misinformation and states: *"Lipedema is not an edema or lymphatic disorder."*

These findings are not simply matters of opinion; they represent published medical research.

A name that implies fluid accumulation when no such accumulation is present is therefore not harmless. It is misleading.

Note: Quotations from Hirsch et al. and the German S2k guideline have been translated from German. All other quotations are presented in the authors' original English wording.

Why We Do Not Perform Manual Lymphatic Drainage in Patients With Lipalgia Syndrome

Every day, we see patients, both in our outpatient and inpatient settings, who have received manual lymphatic drainage for years and continue to request it because they have been told they have edema. The name of the condition reinforces that expectation. In many cases, no one has explained that there is no edema to decongest.

Where there is no edema, there is nothing to decongest.

Since 2021, the Földi Clinic has not treated lipalgia syndrome with manual lymphatic drainage. This decision is not a cost-cutting measure, nor is it a criticism of a treatment that we use routinely and with conviction for patients with lymphedema. It is the logical consequence of what we consider to be an accurate diagnosis.

Importantly, if edema from another cause is present in addition to lipalgia syndrome, such as obesity-associated, primary or secondary lymphedema, for example, that edema is treated with appropriate decongestive therapy. We treat what is present, not what the name suggests.

What Now Comes into Focus: Pain

The cardinal symptom of lipalgia syndrome is not swelling; it is pain. The new name reflects this directly: *lipos* = fat; *algos* = pain.

This places the focus of treatment on what these patients actually experience and brings greater attention to treatments intended to address pain and function:

- **Compression:** In edema, compression helps decongest tissue. In lipalgia syndrome, compression is used to reduce pain and support the soft tissue.
- **Exercise in compression:** Exercise has an anti-inflammatory effect, can influence pain thresholds and may positively affect mood.
- **Psychosocial therapy:** Why psychological therapy? Because in chronic pain conditions such as lipalgia syndrome, physical and emotional factors interact. Addressing both is an important part of comprehensive pain management.
- **Weight management:** Accompanying obesity can substantially influence disease progression. Pharmacologic treatment with GLP-1 receptor agonists and **bariatric surgery** may be appropriate when clinically indicated.

Exercising while wearing compression, psychosocial therapy and treatment of obesity, including bariatric surgery, are recommended with full consensus in the German S2k guideline.

What Does the New Name Mean for You?

We understand that changing the name of a condition can be confusing and may cause uncertainty. Here is what we want you to know:

Your condition is real, recognized and requires appropriate treatment. The new name is intended to make the defining features of the condition clearer to clinicians and patients.

The new name places pain at the center of the condition. It makes clear that pain is an important part of the condition and that treatment should address it.

The “-algia” component of the name highlights the relevance of pain management and the interaction between physical and emotional factors in chronic pain.

Our goal is to move away from decades of misunderstanding, misdiagnosis, inappropriate treatment approaches and unrealistic expectations.

For Physicians and Therapists

The renaming follows an international development.

Lymphoedema Wales led the way by adopting the term *Lipalgia Syndrome* in 2023. The Földi Clinic is now the second institution worldwide to take this step and the first in the German-speaking countries. Klose Training in the United States, the largest and most respected training institution for lymphedema therapists, will follow suit and adopt the term

in its curricula. In addition, in 2023 the German Society of Phlebology and Lymphology and the Union Internationale de Phlébologie launched a joint initiative for a formal renaming process.

We recognize that we are leading this change. We are doing so not to be contrary, but because we believe it is inappropriate to retain a medical term when the condition it describes differs from what the name implies.

Coding and Prescriptions Are Unaffected

The renaming is a matter of terminology, not entitlement. Specifically:

- **The ICD-10 code remains unchanged: E88.28.** There is no change in coding.
- Our medical reports and outpatient and inpatient discharge summaries will now state: **“Lipalgia syndrome (formerly lipedema), E88.28.”** This is intended to make the diagnosis clear to referring practices, garment suppliers and payers.
- The renaming does not expand or restrict claims for compression garments, rehabilitation or other benefits.

For our clinical collaboration, this means:

1. **The two diagnostic criteria** described in the International Consensus and the S2k guideline remain unchanged: a disproportionate increase in adipose tissue of the extremities together with **relevant pain** in that tissue. If there is no relevant pain, a diagnosis of lipalgia syndrome should not be made. “Relevant” means pain that the patient describes as impairing and not simply tenderness elicited during palpation. When disproportionate adipose tissue is present without relevant symptoms, the term lipohypertrophy continues to apply; this condition does not necessarily require treatment.
2. **Leg swelling and a tendency to bruise** are no longer diagnostic criteria for lipalgia syndrome.
3. **Stages** are no longer used, in accordance with the S2k guideline, because the extent of adipose tissue enlargement does not correlate with pain intensity.
4. **The term “lipolymphedema” is discontinued.** Lipalgia syndrome and lymphedema are considered distinctly different conditions that may coexist in the same person. In our view, they have different underlying causes, and neither condition gives rise to the other.
5. **Manual lymphatic drainage is not prescribed** for patients with confirmed, pure lipalgia syndrome. For lymphedema attributable to other causes, we continue to prescribe appropriate treatment.

We recognize that this change will require discussion with patients, clinicians and payers. We welcome those conversations and will make the relevant publications available upon request.

Frequently Asked Questions

Do I now have a different condition? No. You have the same condition as before. It has been given a name intended to describe what you experience: pain associated with disproportionate adipose tissue, without edema.

Do I have to have my medical records changed? No. The ICD-10 code remains E88.28. Our medical reports will now state “Lipalgia syndrome (formerly lipedema), E88.28.” This is intended to make the diagnosis easier for everyone involved to understand.

Will I still receive compression garments? Yes. Compression remains an important part of treatment. In edema, compression helps decongest tissue; in lipalgia syndrome, it is used to relieve pain and support the tissue. Your existing provision of compression garments remains unchanged.

Will I still receive inpatient treatment or rehabilitation? Yes. The renaming does not change the requirements for, or your entitlement to, treatment or rehabilitation.

Why do I no longer receive manual lymphatic drainage? It helped me. We believe you when you say that manual lymphatic drainage helped you, and we do not wish to minimize that experience. Pleasant touch can provide short-term pain relief through well-established neurophysiological mechanisms, but that effect is different from decongestion. We believe that exercise in compression offers greater potential for sustained benefit because it can influence pain thresholds and physical function. We therefore recommend treatment interventions that we believe are most likely to provide long-term benefit.

What if I also have lymphedema? If you also have lymphedema, you will receive appropriate decongestive therapy, including manual lymphatic drainage when indicated. We treat what is present.

Does the new name mean that my pain is “psychological”? No. In chronic pain conditions, physical and emotional factors interact, as they do in conditions such as chronic back pain. Your pain is real. The new name is intended to broaden the focus of treatment, not to suggest that the pain is psychological.

My family doctor does not know the term. What should I do? Bring your medical report with you; it includes both names. Upon request, we will also provide the relevant passages from published papers and guidelines to your health care provider.

Does anything change regarding liposuction? No. The renaming does not change our position regarding liposuction. We consider it appropriate for a small, clearly defined group of patients, such as those with stable body weight, without relevant obesity or significant psychological comorbidity, and after conservative treatment has failed.

For therapists: What do you recommend instead? We recommend exercise therapy and physical activity performed in compression, appropriately fitted flat-knit compression garments, psychosocial support and weight management. When appropriate, pharmacologic treatment with GLP-1 receptor agonists and/or bariatric surgery may also be considered.

Exercise in compression, psychosocial therapy and treatment of obesity, including bariatric surgery, are endorsed with full consensus by the S2k guideline.

Closing Remarks

With this decision, we are discontinuing the use of a term that has been established for decades. That is not easy for us. However, if a term inaccurately describes a condition and contributes to inappropriate treatments and expectations, we believe the potential harm of retaining it is greater than the disruption caused by changing it.

Lipalgia syndrome is not an edema condition. It is not a lymphatic condition. It is a pain condition – and that is how we believe it should be treated.

Dr. med. Tobias Bertsch Chief Physician and Medical Director
Dr. med. Michael Oberlin Chief Physician and Medical Director
Földi Clinic – European Center of Lymphology, Hinterzarten

Sources (Selected)

- German Society of Phlebology and Lymphology. S2k Guideline Lipoedema, Version 5.0, 2024. AWMF Register No. 037-012.
- Hirsch T, Schleinitz J, Marshall M, Faerber G. Ist die Differenzialdiagnostik des Lipödems mittels hochauflösender Sonografie möglich? *Phlebologie*. 2018;47(4):182–187.
- Bertsch T, Erbacher G, Elwell R, Partsch H. Lipoedema: a paradigm shift and consensus. *Journal of Wound Care*. 2020;29(11):1–52.
- Felmerer G, Stylianaki A, Hollmén M, et al. Increased levels of VEGF-C and macrophage infiltration in lipedema patients without changes in lymphatic vascular morphology. *Scientific Reports*. 2020;10:10947. doi:10.1038/s41598-020-67987-3.
- Bertsch T, Erbacher G. Die neue Leitlinie zum Lipödem-Syndrom: mehr Licht als Schatten. *Orthopädie Technik*. 2024;75(12):34–42.
- Erbacher G, Mendoza E, Bertsch T. Thigh swelling in patients with lipedema – subjective perception versus objective examination. *Vasa*. 2022;51(6):386–388.
- von Atzigen J, et al. A Comparative Analysis to Dissect the Histological and Molecular Differences among Lipedema, Lipohypertrophy and Secondary Lymphedema. *International Journal of Molecular Sciences*. 2023;24(8):7591.
- Mackie H, et al. Differentiation of lipoedema from bilateral lower limb lymphoedema by imaging assessment of indocyanine green lymphography. *Clinical Obesity*. 2023;13(3):e12588.
- Stellmaker R, et al. Comparison of fluid and body composition measures in women with lipoedema, lymphoedema, and control participants. *Clinical Obesity*. 2024;14(4):1–9.
- Cellina M, et al. Non-contrast MR Lymphography of lipedema of the lower extremities. *Magnetic Resonance Imaging*. 2020;71:115–124.