

Lipoedema Syndrome – More Than Just Big Legs

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Summary

This lecture presents a **paradigm shift** in the diagnosis and treatment of lipoedema syndrome – one that originated at the Földiklinik and is now supported by the International Lipoedema Association (ILA), the International Consensus Document (2020) and the German AWMF S2k guideline published in 2024. The core thesis: lipoedema syndrome is **neither an oedema disorder nor a condition involving venous or lymphatic dysfunction**. It is a pain disorder in disproportionately increased adipose tissue – embedded in a biopsychosocial comorbidity structure in which two factors govern the course of the disease: a marked **pre-existing psychological burden** and **obesity** that, in the majority of cases, requires treatment. Anyone who looks only at the legs overlooks the principal disease – with potentially life-shortening consequences.



Act I – Pain and Psyche: Why More Is Needed Than an Examination of the Legs

The earlier lymphological reading of lipoedema as an “oedema disease with lymphatic insufficiency” is scientifically untenable. The international ILA consensus and the 2024 AWMF S2k guideline state this unambiguously:

“Lipoedema is primarily neither an oedema disorder nor a condition involving venous or lymphatic dysfunction.” — AWMF S2k Guideline on Lipoedema, 2024

If oedema plays no role, we must explain the pain differently – and without the detour via lymphatic insufficiency. On this point the guideline records a clinically decisive finding: **the pain symptomatology does not correlate with the degree of disproportion, or with the increase in subcutaneous adipose tissue**. Two patients – for example, one with a BMI of 29 and one with a BMI of 52 – may report identical pain scores (VAS 9/10) and identical pain-related limitations; a patient with little increase in fat may suffer more than one with pronounced disproportion. The consequence: staging classifications are now obsolete in lipoedema, and the Földiklinik no longer uses them.

The Psychological Dimension – Cause, Not Consequence

The Földiklinik’s pivotal study (Erbacher & Bertsch 2020, N = 150) shows that **more than 80% of patients with a confirmed lipoedema syndrome carry a serious psychological burden** – and do so as early as the *year before* the onset of lipoedema pain. What precedes in time cannot, by formal logic, be a consequence of the pain. **52% of patients report traumatic experiences** (sexual abuse or physical

violence). The link between traumatic experience and pain perception in general is independently confirmed by a systematic review of more than 17,000 participants (Marin et al., Children 2021): sexual and physical abuse in particular are associated with a markedly elevated risk of chronic pain.

Methodologically, our study is not trivial: 150 women with a medically confirmed lipoedema syndrome were assessed in two semi-structured interviews – one on their history of psychological burden (operationalised through manifest ICD-10 F-diagnoses such as depression, eating disorder or post-traumatic stress disorder, as well as serious psychological disturbances such as burnout or chronic stress), the second on the development of the pain symptomatology typical of lipoedema. The two timelines were then aligned **together with the patients** – an approach that makes it possible to reconstruct temporal sequences that are hard to establish by purely retrospective means. This makes the narrative common in lipoedema forums and on talk shows – that the psychological burden is merely a *consequence* of lipoedema syndrome (“the women suffer simply because of how their legs look”) – incompatible with the data.

Pain research describes a self-reinforcing cycle between stress and pain: stress lowers pain tolerance while at the same time impairing the emotional regulation needed to cope with pain (recent data from the Central Institute of Mental Health, Mannheim). Stress activates the nervous system and simultaneously weakens precisely those psychological resources with which the amplified pain might be managed; each component drives the other. Three levels interlock within this spiral: **physical factors** such as the low-grade inflammation in the adipose tissue, which lowers pain thresholds and reinforces central sensitisation; **cognitive-emotional factors** such as fear of pain, catastrophising rumination and negative expectations, which are not a matter of “mood” but measurable modulators of pain processing; and **social factors** such as lack of support, experiences of stigmatisation and the repeated experience of medical bewilderment. Psychological trauma, chronic stress and chronic pain are processed in the same limbic structures – essentially the amygdala, the hippocampus, and the anterior cingulate and insular cortex. Here psychology becomes measurable biology.

Words Have Power – and Are Therefore a Powerful Part of the Therapy

One pragmatic consequence of these findings: **the physician’s explanation of the pathophysiology of lipoedema pain alone measurably lowers pain scores** on the VAS – in our study typically by 1–2 points from baseline values of 7 to 9, with the effect lasting one to two days, until the actual therapy begins (Erbacher & Bertsch, 2020). The intervention consisted of nothing more than this: explaining the mechanisms of how the pain arises and how it can be relieved; making clear that those affected are not “to blame”, but that many factors contribute to lipoedema pain.

Moseley (2005) documented the neurobiological correlate on functional MRI: in a patient with chronic back pain, a week of physiotherapy delivered by an excellent therapist changed almost nothing in the activity of the pain-processing brain regions; the following week of identical therapy – *after* the patient

had been given a clear explanation of *why* these exercises work – showed a dramatic decline in that activity, and in the pain the patient experienced.

What physicians, therapists and medical-supply retail staff say – and how they say it – is not an incidental extra but an effective component of the therapy. At the Földiklinik these findings are put into practice in psychologically led lipoedema workshops; from more than 450 group sessions (>5,000 votes cast), three core topics chosen by the patients themselves have crystallised: **regulating stress, dealing with difficult emotions, and self-acceptance.**



Act II – The Repressed Principal Diagnosis: Obesity

Anyone who sets out to treat lipoedema without talking about obesity treats everything but the essential. The evidence is overwhelmingly consistent: **around 85% of patients with lipoedema are obese (BMI > 30), and about 50% have severe obesity (BMI > 40)** – documented concordantly by Child et al. 2010, Dudek et al. 2018, Erbacher & Bertsch 2020, Fink et al. 2020, Angst et al. 2021 and Clarke 2024. Only around 4% of patients are of normal weight.

Obesity Is a Lethal Disease

Mortality follows a clear dose-response relationship. Data from the Bremen Heart Centre show that people with a normal BMI have almost an 80% probability of reaching the age of 70. At a BMI of 35–40 this probability falls to 60%; **at a BMI of 40–50, only one in two patients reaches the age of 70.** Since 2012, more people worldwide have died from the consequences of obesity than from hunger; in the United States, the first generation is growing up whose life expectancy is lower than that of its parents.

The Myth of “Pathological Fat”

In public discourse – talk shows, social media, self-help forums – lipoedema is misused as an explanation for excess weight: women “have lipoedema, not obesity”; the fat supposedly “proliferates” independently of the energy balance. This narrative is physically impossible. A review from Harvard (Westcott & Rosen, Endocrinology 2022) puts it plainly:

“Obesity results from a net positive energy balance and not from the differentiation of new fat cells.” — Westcott & Rosen, Endocrinology 2022

Adipogenesis is a *consequence* of overnutrition, not an independent cause. Lymphoedema or genetic factors can influence *where* fat is stored, but they cannot create fat mass without an energy surplus. The first law of thermodynamics holds in our patients’ legs too.

Diagnostic Inflation and a Questionable Business Model

At Germany's two largest lymphological centres – the Charité in Berlin and the Földiklinik in Hinterzarten – **76–82% of referral diagnoses of lipoedema were incorrect** in 2023. The reasons are structural: self-diagnosis via online portals, diagnostic apps, remote diagnoses from photographs without physical examination – and an aggressively marketed liposuction industry that has a commercial interest in the diagnosis of lipoedema. We know of no other medical treatment that is marketed as aggressively as liposuction for lipoedema. One looks in vain for advertising videos promoting chemotherapy, stent implantation or complex decongestive therapy.

This is *not* a blanket rejection of liposuction. It has its place in carefully selected individual cases – as the contributions of Hildur Skuladottir and Axel Baumgartner at this symposium demonstrate. What is questionable is the indication: patients whose principal problem is obesity are channelled towards a treatment that leaves their life-shortening underlying disease untreated.

Conservative Weight Reduction: 95% Fail

Diets, dietary changes, exercise programmes – their success rate over a five-year horizon is around 5%. The Finnish FinnTwin study of 4,000 twins over 15 years reaches a conclusion that is paradoxical at first glance: **the more often people diet, the higher their BMI after 15 years**. This failure is universal – independent of sex, age and the presence of lipoedema. It has nothing to do with lipoedema.



Act III – A Holistic Treatment Concept

Stigmatisation Is Part of the Problem

Society – and, regrettably, the healthcare system too – reads obesity as the consequence of personal failure: weakness of will, lack of discipline, self-neglect. A study from Johns Hopkins University, which made the front page of the *New York Times*, documents that physicians communicate more empathetically with slimmer patients than with obese ones. This stigmatisation is one of the principal engines of the lipoedema hype: a diagnosis of lipoedema allows patients to escape the stigma trap of “your own fault” – at the price of leaving the genuinely treatable disease untreated.

The first therapeutic step is therefore a change of attitude: **obesity is a chronic disease, like diabetes, coronary heart disease or osteoarthritis** – with a complex aetiology, treatable, rarely curable. Here too, empathy and a sound relationship of trust are the precondition for any effective therapy.

Pillars of Treatment

The concept practised at the Földiklinik and co-endorsed by the ILA rests on the following pillars:

1. Patient information and pain education. The physician's communication of the pathophysiology is demonstrably pain-reducing. It is the first, the least expensive and a biologically highly effective intervention.

2. Psychosocial therapy. Regulating stress, working through difficult emotions, self-acceptance – structured at the Földiklinik through psychologically led group workshops, supplemented by individual therapy, for example for trauma-related disorders.

3. Physiotherapy and exercise therapy. No cure for obesity, but indispensable for mobility, pain modulation, weight stabilisation and quality of life.

4. Compression therapy. Indicated because of its anti-inflammatory effect – not for the “decongestion” of an oedema that does not exist.

5. Nutritional therapy. Counselling in groups and individual sessions, with practical training in the clinic’s own teaching kitchen. Realistic management of expectations: conservative measures rarely reduce weight in a lasting way, but play an important role in weight stabilisation.

6. Pharmacotherapy of obesity. GLP-1 and GIP/GLP-1 receptor agonists (semaglutide, tirzepatide) enable weight reductions of up to roughly 20%. The treatment is lifelong; reimbursement – outside of diabetes – is barely obtainable.

7. Bariatric surgery. Sleeve gastrectomy and Roux-en-Y gastric bypass are the most effective option in severely obese patients with lipoedema syndrome. Since 2008, the Földiklinik has systematically prepared patients with obesity plus lymphoedema, or plus lipoedema, for bariatric procedures. The study by Fink et al. (Visc Med 2021), published jointly with the University Medical Center Freiburg, provides the evidence base: in a retrospective cohort (n = 31 lipoedema patients, 14 controls with distal leg lymphoedema), sleeve gastrectomy and Roux-en-Y bypass led to a significant and durable reduction in thigh volume of around 30–33% after 10–18 months – precisely in the patient group that classical teaching held to be “diet-resistant”. The clinical courses shown in the lecture illustrate the significance of these findings – provided that the principal diagnosis of obesity is consistently brought to the fore.

8. Liposuction. Only in carefully selected individual cases with a BMI below 32, after conservative – and, where indicated by a high BMI, bariatric – options have been exhausted.



Take-home messages

- Lipoedema syndrome is not an oedema-related or lymphological disease, but a pain disorder in disproportionate adipose tissue.
- Pain does not correlate with the amount of adipose tissue; staging classifications are therefore obsolete. To date, no staging system exists for the symptoms of lipoedema syndrome.
- More than 80% of patients carry a substantial psychological burden *before* the onset of lipoedema pain; 52% report traumatic experiences – which has a considerable influence on pain perception.

- Around 85% of patients are obese, about 50% severely so. Obesity is the most common and most dangerous comorbidity.
- Obesity arises from a positive energy balance – not from lipoedema itself. The first law of thermodynamics holds in lipoedema syndrome too.
- Up to four in five referral diagnoses of lipoedema are incorrect. Liposuction risks becoming a business model at the expense of untreated obesity – and thus at the expense of the health of patients with obesity and lipoedema syndrome.
- Effective therapy is holistic: patient education, psychosocial support, exercise, compression, nutrition, pharmacological and – where indicated – bariatric therapy. Liposuction remains an individual-case indication.

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