

How do we diagnose lipedema?

Recommendation of the Diagnosis Working Group of the International Lipoedema Association

By Anna Towers

Research on lipedema is in its infancy, and there is, as yet, no internationally recognized diagnostic scheme for the syndrome. This leads to a vicious circle. How can patients be recruited for research into this poorly understood condition if we cannot define inclusion criteria and diagnose it in a way that is accepted worldwide?

To advance knowledge of this condition, the International Lipoedema Association (ILA – theila.net) was founded in 2021 by 60 multidisciplinary healthcare providers from 22 countries. Working in partnership with the International Lymphoedema Framework, the mission of the ILA is to improve our understanding of lipedema and to raise standards of care based on clinical evidence, long-standing experience, and a passion for improved therapy outcomes.

FIGURE 1



ILA Diagnosis Group members (left to right, top to bottom): C. Ure, A. Towers, H. Brorson, D. Corda, C. Pomata, F. Greco, L. Perbeck.

To start dealing with the important issue of diagnosis, in November 2021, the ILA created a Diagnosis Working Group consisting of seven experts. Using existing scientific reviews, their role was to reach a consensus about what criteria should form the basis for a lipedema diagnosis.



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ILA Diagnosis Working Group members

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Current understanding of lipedema

As stated on the ILA website, Lipoedema-Syndrome is a chronic condition in women characterized by two main criteria:

- 1 Disproportionate increase in adipose tissue in the legs (sometimes in the arms) plus
- 2 Pain and/or tender to touch skin (allodynia) in the adipose tissue.

This means that adipose legs without at least the abnormal pain cannot be diagnosed as lipedema.

However, how do we better define the pain associated with lipedema? Are there other symptoms that can help determine the diagnosis?

Many co-existing conditions have been described in lipedema patients. In addition to abnormal sensitivity to pain, most patients with lipoedema also suffer from:

- Overweight and obesity (which is a chronic disease independent of lipedema)
- Reduced physical fitness
- Mental issues such as chronic anxiety, depression, or eating disorders
- Lack of self-acceptance because of the current beauty ideal
- Psychosocial issues (financial, health insurance coverage for treatments etc.)

These co-existing conditions may make diagnosis challenging and will impact management.

Working towards diagnostic criteria for the lipedema syndrome

The physicians and surgeon members of the Diagnosis Working Group met extensively via remote video-conferencing during 2022. These meetings were recorded and transcribed. Members then reviewed the transcriptions and added comments or questions that were carried over to future meetings. Using the PICO investigative model¹, the Working Group assessed each potential diagnostic element, referred to the existing literature, plus their combined clinical experiences, and reached a consensus regarding a recommended Diagnostic Scheme that was subsequently reviewed and supported by the ILA Board.

In a parallel process, the group carefully examined the useful diagnostic criteria from the *Dutch Guidelines for Lipedema*² and evaluated which elements do and do not have a significant scientific basis at this time.

Some of the broad questions that the Working Group discussed over the course of their meetings and deliberations:

- 1 What are the challenges in making a lipedema diagnosis?
- 2 How can a clinician diagnose lipedema using easily available and non-invasive methods?
- 3 Which elements should be considered, and which should be excluded?
- 4 How should the retained elements be weighted in the final diagnostic scheme or guide?
- 5 What do we know about the prevalence of lipedema, acknowledging the serious lack of knowledge among general healthcare providers, and the lack of formal diagnostic criteria?

TABLE 1

The Diagnostic Scheme that the Working Group recommended

Diagnosis of lipoedema may be made when all the following major criteria are present: A1, A2, A3

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|---|---|---|
| A | 1 | Disproportionate subcutaneous fatty tissue distribution between upper and lower body, which is symmetrical |
| | 2 | Reported enhanced sensitivity to touch in the affected areas with objective allodynia (elicited pain) on a pinch test |
| | 3 | Normal hands and feet (in the absence of obesity or lymphedema complications) |

B1 is a minor criterion that may be present or absent. It serves to reinforce the diagnosis.

- | | | |
|---|---|--|
| B | 1 | Significantly thickened subcutaneous fat in lower or/and upper extremity with sudden stop at the joints ("cuff sign" at ankle, elbow or wrist) |
|---|---|--|

Recommended Diagnostic Criteria for Lipedema - ILA Working Group on Diagnosis, supported by the ILA Board, Dec 2022.

Many sub-questions were also discussed, including:

- 1 How do we define lipohypertrophy as opposed to normal fat distribution?
- 2 What is normal versus abnormal pain in patients with suspected lipedema? What is the specific type of pain found in lipedema, and how should we assess it in reaching a diagnosis?
- 3 Is lymphedema a complication of lipedema and/or part of the diagnosis and progression of lipedema?
- 4 Does 'pure' lipedema, as such, progress? Can lipedema be staged, and if so, how?
- 5 What is the link between lipedema and obesity?
- 6 Is there edema in lipedema?
- 7 In those with obesity, what is the impact of weight loss on lipedema limbs?

Many of the above questions are answered in the excellent *Consensus Document*³ published in 2020, which the Working Group reviewed, and which we recommend all involved health care providers use as a reference. This publication is available on the International Lipoedema Association website, along with other very useful references.

The Diagnosis Working Group members kept the following important considerations in mind during their deliberations:

- 1 High-level research evidence is lacking. The main sources consulted were existing consensus documents and guidelines that are based on previously conducted critical reviews of the literature.

- 2 At this time, for lipedema diagnostic criteria to be most useful to clinicians, diagnosis needs to be made using simple, non-interventionist medical history and physical examination, avoiding expensive and less available imagery or other diagnostic interventions.

There are also important socioeconomic considerations that impact lipedema patients. The Working Group members, clinicians and clinical scientists, understand the reality of the clinical world in terms of socioeconomic factors and resources available. One important problem raised by lipedema patients concerns insurance coverage for decongestive lymphatic therapy and surgical treatments – for which patients come seeking a medical diagnosis that the insurance provider will accept.

Finally, there is a critical research consideration. Future research will further clarify the effectiveness of available treatments for lipedema. However, the problem of how to diagnosis lipedema in the first place remains central to clinical and research development. Internationally accepted diagnostic criteria are of course, essential in choosing patients for clinical trials.

How do we clinically assess the pain associated with lipedema?

The particular type of pain that defines lipedema is allodynia (pain due to a stimulus that does not normally provoke pain; for example, light touch). The question of how a clinician should test for allodynia is important. Many patients with lipedema features will

complain of pain that could be due to many factors and related disorders. Therefore, the clinician cannot rely on the anamnesis (patient reported medical history) or clinical history. The Working Group at the time suggested that the assessment for allodynia be done with a "pinch test" in the involved areas at the time of the physical examination. Further discussions that I have personally had with colleagues have led to ethical questions and considerations about trying to provoke pain on examination while a patient is distracted! A colleague has suggested that we test for allodynia as we test for pitting edema, which in the case of potential co-existing lymphedema, should involve pressure over the site (usually thigh or calf) for up to one minute. In the case of suspected lipedema, this will provoke allodynia.

Conclusion

Research is urgently required regarding the lipedema syndrome. The Working Group of the ILA produced a recommended diagnostic scheme that was supported by the ILA Board in December 2022. An internationally recognized diagnostic scheme for lipedema will facilitate further research, thus enhancing our understanding of this syndrome in all its aspects – ultimately refining the diagnostic process itself.

Anyone with a special interest in this disorder is invited to join the ILA. Membership is open to physicians, specialized nurses, psychologists, physiotherapists, dieticians, and researchers in the field of lipedema as well as other healthcare professionals with a specific interest in lipedema, including professionals employed by the medical device and pharmaceutical industry. [LP](#)

The full text of the Working Group report is available on the member section of the International Lipoedema Association website (theila.net).

References

1. PICO model: <https://researchguides.uic.edu/c.php?g=252338&p=3954402>. Accessed 2023-06-20.
2. Halk AB, Damstra RJ. First Dutch guidelines on lipedema using the international classification of functioning, disability and health. *Phlebology* 2017, Vol. 32(3) 152-159.
3. International Consensus document, "Lipoedema: a paradigm shift and consensus." *Journal of Wound Care*, Vol 29, Supp 2(11), 2020.