

Lipedema Quality of Life Survey (LipQoL)

This questionnaire has been designed for patients with lipedema. Please tick the box that best describes how you feel today about each of the questions. This survey is a tool to help you understand and communicate the impact of lipedema on your quality of life. Share your results with your healthcare provider to guide discussions about your care and treatment plan.

Sex Assigned at Birth:

Name: _____ **Age:** _____ **Date:** _____

A. Physical Symptoms and Mobility:	Not at all / Never	A little / Rarely	Moderately / Sometimes	Quite a bit / Often	Extremely / Always
1. How much pain do you experience in your affected areas?					
2. How often do you feel heaviness in your limbs?					
3. How much does lipedema affect your ability to walk?					
4. How often do you experience easy bruising?					
5. How much does lipedema affect your balance?					
6. How often do you experience swelling in your affected areas?					
7. How much does lipedema affect your ability to exercise?					
8. How often do you experience skin sensitivity in affected areas?					
9. How much does lipedema affect your sleep quality?					
10. How often do you experience fatigue due to lipedema?					
Total Boxes Checked Per Column:					
Multiply Row Above by	X1	X2	X3	X4	X5
TOTAL					
Add up TOTAL from Each Column					
Divide by 10					
Round to one decimal place – Score A					

B. Everyday Life and Activities:	Not at all / Never	A little / Rarely	Moderately / Sometimes	Quite a bit / Often	Extremely / Always
11. How much difficulty do you have finding comfortable clothing?					
12. How often does lipedema interfere with your daily activities?					
13. How much does lipedema affect your ability to perform household chores?					
14. How often do you avoid activities due to lipedema?					
15. How much does lipedema affect your personal hygiene routines?					
16. How often does lipedema impact your food choices or eating habits?					
17. How much does lipedema affect your ability to travel?					
18. How often does lipedema interfere with your work or studies?					
19. How much does lipedema affect your leisure activities?					
20. How often do you need to rest during the day due to lipedema?					
Total Boxes Checked Per Column:					
Multiply Row Above by	X1	X2	X3	X4	X5
TOTAL					
Add up TOTAL from Each Column					
Divide by 10					
Round to one decimal place – Score B					

C. Social Life and Relationships:	Not at all / Never	A little / Rarely	Moderately / Sometimes	Quite a bit / Often	Extremely / Always
21. How much does lipedema affect your social interactions?					
22. How often do you feel self-conscious about your appearance in public?					
23. How much does lipedema impact your intimate relationships?					
24. How often do you avoid social gatherings due to lipedema?					
25. How much does lipedema affect your family relationships?					
26. How often do you feel misunderstood by others regarding your condition?					
27. How much does lipedema impact your ability to make new friends?					
28. How often do you feel isolated due to lipedema?					
29. How much does lipedema affect your confidence in social situations?					
30. How often do you feel judged by others due to your appearance?					
Total Boxes Checked Per Column:					
Multiply Row Above by	X1	X2	X3	X4	X5
TOTAL					
Add up TOTAL from Each Column					
Divide by 10					
Round to one decimal place – Score C					

D. Emotional Well-being:	Not at all / Never	A little / Rarely	Moderately / Sometimes	Quite a bit / Often	Extremely / Always
31. How often do you feel anxious about your lipedema?					
32. How much does lipedema affect your self-esteem?					
33. How often do you feel frustrated by your condition?					
34. How much does lipedema contribute to feelings of depression?					
35. How often do you worry about the progression of your lipedema?					
36. How much does lipedema affect your body image?					
37. How often do you feel discouraged about managing your lipedema?					
38. How much does lipedema affect your overall mood?					
39. How often do you feel overwhelmed by your condition?					
40. How much does lipedema impact your sense of control over your life?					
Total Boxes Checked Per Column:					
Multiply Row Above by	X1	X2	X3	X4	X5
TOTAL					
Add up TOTAL from Each Column					
Divide by 10					
Round to one decimal place – Score D					

E. Treatment and Management:	Not at all / Never	A little / Rarely	Moderately / Sometimes	Quite a bit / Often	Extremely / Always
41. How satisfied are you with your current lipedema treatment?					
42. How often do you wear compression garments?					
43. How much does manual lymphatic drainage help manage your symptoms?					
44. How often do you engage in lipedema-specific exercises?					
45. How satisfied are you with the support from your healthcare providers?					
46. How often do you research about lipedema and its management?					
47. How much financial strain does lipedema treatment cause you?					
48. How often do you follow a specific diet to manage lipedema?					
49. How satisfied are you with your ability to manage your lipedema?					
50. How often do you feel pessimistic about future treatments for lipedema?					
Total Boxes Checked Per Column:					
Multiply Row Above by	X1	X2	X3	X4	X5
TOTAL					
Add up TOTAL from Each Column					
Divide by 10					
Round to one decimal place – Score E					

Total Score	Score Interpretation Guide
Score A	
Score B	1.0 - 2.0: Minimal impact on quality of life
Score C	2.1 - 3.0: Moderate impact on quality of life
Score D	3.1 - 4.0: Significant impact on quality of life
Score E	4.1 - 5.0: Severe impact on quality of life
Total Score	
Divide by 5	

Tracking Progress: Keep a record of your scores over time to track changes in your quality of life. Compare domain scores to identify areas that may need more attention or support.