

Lymphedema Quality of Life Inventory (LyQLI)

This questionnaire is concerned with the way lymphedema may affect your quality of life and activities of daily living.

You may have experienced very mild lymphedema, moderate or severe symptoms. You may have lived with your symptoms for a short or long period of time.

Please answer these questions only as they concern your lymphedema

The questionnaire consists of three parts

- Physical
- Psychosocial
- Practical

Please think about your Lymphedema and your Quality of Life during **the past four weeks**. When it comes to questions that depend on seasons, think about the **past year**.

For each question circle the answer that best matches your experiences. **Try to answer all questions. If a question does not seem to apply to you, please circle the choice that says "None"**

Physical concerns due to lymphedema		How much do these concerns affect your quality of life?			
1	Pain/aches due to my lymphedema	None	A little bit	Somewhat	A lot
2	Discomfort due to my lymphedema	None	A little bit	Somewhat	A lot
3	A feeling of heaviness due to my lymphedema	None	A little bit	Somewhat	A lot
4	Pins and needles/numbness due to my lymphedema	None	A little bit	Somewhat	A lot
5	Burning sensation/heat due to my lymphedema	None	A little bit	Somewhat	A lot
6	Swelling/tightness due to my lymphedema	None	A little bit	Somewhat	A lot
7	Skin problems due to my lymphedema	None	A little bit	Somewhat	A lot
8	Difficulty sleeping due to my lymphedema	None	A little bit	Somewhat	A lot
9	Movement difficulties due to my lymphedema	None	A little bit	Somewhat	A lot
10	Feeling physically aware of my lymphedema all the time	None	A little bit	Somewhat	A lot
11	Feeling a loss of strength in the swollen part of my body	None	A little bit	Somewhat	A lot
12	Infection (e.g. cellulitis, erysipelas)	None	A little bit	Somewhat	A lot

Psychosocial concerns due to lymphedema		How much do these concerns affect your quality of life?			
13	Feelings of frustration/feeling annoyed	None	A little bit	Somewhat	A lot
14	Feeling anxious about whether or not the lymphedema will get worse	None	A little bit	Somewhat	A lot
15	Embarrassed by lymphedema/compression garments	None	A little bit	Somewhat	A lot
16	Negative changes in how I see myself	None	A little bit	Somewhat	A lot
17	Feeling discouraged	None	A little bit	Somewhat	A lot
18	Not being able to do the things I used to enjoy	None	A little bit	Somewhat	A lot
19	Concerns about when to seek medical attention	None	A little bit	Somewhat	A lot
20	Paying constant attention to my condition	None	A little bit	Somewhat	A lot
21	Concerns about how my lymphedema affects my existing relationships	None	A little bit	Somewhat	A lot
22	Concerns about how lymphedema could affect new relationships	None	A little bit	Somewhat	A lot
23	Negative changes in my feelings about intimacy/sexuality	None	A little bit	Somewhat	A lot
24	Feeling uncomfortable/embarrassed while doing sports and hobbies	None	A little bit	Somewhat	A lot
25	Feeling uncomfortable/embarrassed when attending social activities with friends and at work	None	A little bit	Somewhat	A lot
26	Having to ask for help in different situations	None	A little bit	Somewhat	A lot
27	Concerns about negative changes in my appearance	None	A little bit	Somewhat	A lot
28	Having to answer questions about my lymphedema	None	A little bit	Somewhat	A lot

Practical concerns due to lymphedema		How much do these concerns affect your quality of life?			
29	Personal activities of daily living (e.g. dressing, combing hair, foot care)	None	A little bit	Somewhat	A lot
30	Normal daily activities (e.g. doing housework, sports- and hobby activities)	None	A little bit	Somewhat	A lot
31	Employment activities	None	A little bit	Somewhat	A lot
32	Learning to do things differently	None	A little bit	Somewhat	A lot
33	Having less energy to do activities (e.g. personal, normal daily or employment)	None	A little bit	Somewhat	A lot
34	Financial costs of managing my lymphedema (e.g. clothes, shoes, treatments, garments)	None	A little bit	Somewhat	A lot
35	Finding well-functioning compression garments (e.g. stockings, sleeves, gloves)	None	A little bit	Somewhat	A lot
36	Traveling long distances by car, train, plane etc.	None	A little bit	Somewhat	A lot
37	Finding clothes and shoes that are comfortable and attractive, the right size and type of material	None	A little bit	Somewhat	A lot
38	Limitations in hot weather/sun	None	A little bit	Somewhat	A lot
39	The constant self-care I need to do to stop my lymphedema from getting worse	None	A little bit	Somewhat	A lot
40	Obtaining information about how to manage my lymphedema	None	A little bit	Somewhat	A lot
41	Being prepared for emergencies (e.g. always having a script for antibiotics)	None	A little bit	Somewhat	A lot

42. In terms of your lymphedema, has this been a typical four week period for you?
Yes () No ()

43. If you answered "No" to the question above, has this period been (tick one)

Much Worse () Worse () Better () Much Better () than usual

44. Please think about how your lymphedema has affected you in the past four weeks and circle the number below that best matches your experience with lymphedema.

0

1

2

3

Very bad

Very good

45. Taking all parts of your life into consideration, how would you describe your quality of life in the past four weeks? Please circle the number below that best matches your overall quality of life.

0

1

2

3

Very bad

Very good

Thank you for your time completing this questionnaire!