



LYMPHOEDEMA NEEDS QUESTIONNAIRE
-BREAST CANCER
(LNQ-BC)

This survey was developed by: The Cancer Education Research Program
Locked Bag 10
WALLSEND NSW 2289
ph: 4924 6372
fax: 4924 6208
email: cerp@newcastle.edu.au

INSTRUCTIONS

To help us plan better services for people diagnosed with lymphoedema of the arm following breast cancer treatment, we are interested in whether or not needs which you may have faced as a result of having lymphoedema have been met.

For every item on the following pages, indicate whether you have needed help with this issue within the last 3 months as a result of having lymphoedema of the arm. Put a circle around the number which best describes whether you have needed help with this in the last 3 months. There are 6 possible answers to choose from:

- | | | |
|-----|---|---|
| 1 = | No need: N/A (Not applicable) | eg: Within this timeframe this was not a problem for me as a result of having lymphoedema of the arm. |
| 2 = | No need: Satisfied | eg: Within this timeframe I did need help with this, but my need for help was satisfied at the time. |
| 3 = | Some need: Low need for help | eg: Within this timeframe this item caused me little concern or discomfort. I had little need for additional help. |
| 4 = | Some need: Moderate need for help | eg: Within this timeframe this item caused me some concern or discomfort. I had some need for additional help. |
| 5 = | Some need: High need for help | eg: Within this timeframe this item caused me a lot of concern or discomfort. I had a strong need for additional help. |
| 6 = | Some need: Some need for help more than 3 months ago | eg: This item has caused me concern as a result of having lymphoedema of the arm, but it was more than 3 months ago |

For example:

In the last 3 months	No need		Some need			Some need But more than 3 months ago
what was your level of need for help specifically in relation to your <u>lymphoedema</u> :	Not Applicable	Satisfied	Low need	Moderate need	High need	
1. Assistance with massage	1	2	3	4	5	6
<p>If you put the circle at 2 it means in the last 3 months you had some level of need with this issue. However, that need has already been met.</p> <p>If you put the circle at 4 it means that in the last 3 months you had some need with this issue that has not been met and this level of need was moderate.</p> <p>If you put the circle at 6 it means that since your breast cancer treatment you've had some level of need for help with this issue but not within the last 3 months.</p>						

In the last 3 months what was your level of need for help in the following areas specifically in relation to your <u>lymphoedema</u> :		No need		Some need			Some need But more than 3 months ago
		N/A	Satisfied	Low need	Moderate need	High need	
1	Dealing with fears about losing your independence as a result of lymphoedema	1	2	3	4	5	6
2	Coping with anxiety about having any treatment for lymphoedema	1	2	3	4	5	6
3	Dealing with fears about physical disability from lymphoedema	1	2	3	4	5	6
4	Dealing with fears about deterioration of your lymphoedema	1	2	3	4	5	6
5	Coping with frustration from not being able to do the things you used to do	1	2	3	4	5	6
6	Dealing with feelings of self blame or guilt about why this has happened to you	1	2	3	4	5	6
7	Dealing with feelings of stress because the lymphoedema is a reminder of breast cancer	1	2	3	4	5	6
8	Dealing with limitations in recreational activities	1	2	3	4	5	6
9	Dealing with feelings of stress because the lymphoedema advertises to others that you had breast cancer	1	2	3	4	5	6
10	Coping with feeling socially isolated because you can't do the things you used to do	1	2	3	4	5	6
11	To have the opportunity to talk to someone who understands and has been through a similar experience	1	2	3	4	5	6
12	Help with learning to feel in control of your situation	1	2	3	4	5	6
13	Coping with frustration with the lack of assistance in dealing with the lymphoedema	1	2	3	4	5	6
14	Coping with reduced self esteem due to the lymphoedema	1	2	3	4	5	6
15	Coping with anxiety when going out because of the appearance of your arm	1	2	3	4	5	6
16	Coping with public ignorance about lymphoedema	1	2	3	4	5	6
17	Coping with changes in other people's attitudes and behaviour towards you since the lymphoedema	1	2	3	4	5	6
18	To have access to vocational assistance/counselling for help in adjusting to having lymphoedema	1	2	3	4	5	6
19	To be given a full explanation of those tests and treatments for which you would like explanations	1	2	3	4	5	6
20	To be given information (written, diagrams, drawings) about aspects of managing your lymphoedema	1	2	3	4	5	6

In the last 3 months what was your level of need for help in the following areas specifically in relation to your <u>lymphoedema</u> :		No need		Some need			Some need But more than 3 months ago
		N/A	Satisfied	Low need	Moderate need	High need	
21	To be adequately informed about the treatment options (benefits and side-effects) for lymphoedema before you choose to have them	1	2	3	4	5	6
22	To be fully informed about the causes of lymphoedema	1	2	3	4	5	6
23	To be informed about alternative therapies for treatment of lymphoedema	1	2	3	4	5	6
24	To be fully informed about lymphoedema support groups in your area	1	2	3	4	5	6
25	To provide family members with information about lymphoedema	1	2	3	4	5	6
26	To be informed of the availability of lymphoedema treatment centres	1	2	3	4	5	6
27	To receive consistent lymphoedema treatment information that does not vary between sources	1	2	3	4	5	6
28	To receive adequate information about lymphoedema from your doctor specifically	1	2	3	4	5	6
29	To be notified of the risks of developing lymphoedema following treatment for breast cancer	1	2	3	4	5	6
30	To be given information about lymphoedema when first diagnosed with breast cancer	1	2	3	4	5	6
31	To be given access to an assessment program for early detection of lymphoedema	1	2	3	4	5	6
32	To be referred to a specifically trained lymphoedema physiotherapist	1	2	3	4	5	6
33	Dealing with pain from the lymphoedema	1	2	3	4	5	6
34	Coping with not sleeping well because of the lymphoedema	1	2	3	4	5	6
35	Coping with work around the home	1	2	3	4	5	6
36	Dealing with reduced physical mobility because of the lymphoedema	1	2	3	4	5	6
37	To be fully informed about techniques and activities you can do to help yourself manage lymphoedema	1	2	3	4	5	6
38	Help with overcoming difficulties with daily activities because of the lymphoedema	1	2	3	4	5	6
39	Finding time for completing routines to manage lymphoedema (massage, exercise, skin care etc.)	1	2	3	4	5	6
40	Coping with waiting a long time for clinic appointments	1	2	3	4	5	6

In the last 3 months what was your level of need for help in the following areas specifically in relation to your <u>lymphoedema</u> :		No need		Some need			Some need But more than 3 months ago
		N/A	Satisfied	Low need	Moderate need	High need	
41	Having health care professionals (eg nurses) fully informed about lymphoedema	1	2	3	4	5	6
42	Having doctor(s) who are fully informed about lymphoedema and its associated problems	1	2	3	4	5	6
43	To have competent, up-to-date treatment	1	2	3	4	5	6
44	Having doctor(s) acknowledge that lymphoedema is a serious condition	1	2	3	4	5	6
45	Having doctor(s) willing to treat lymphoedema	1	2	3	4	5	6
46	Having doctor(s)/ health care professionals willing to follow up with your lymphoedema treatment	1	2	3	4	5	6
47	Coping with the loss of confidence due to lymphoedema	1	2	3	4	5	6
48	Coping with high levels of self consciousness due to lymphoedema	1	2	3	4	5	6
49	Accepting changes in your appearance	1	2	3	4	5	6
50	Availability of clothes to hide arm	1	2	3	4	5	6
51	Coping with embarrassment caused by the appearance of the arm affected by lymphoedema	1	2	3	4	5	6
52	Avoiding social situations due to the lymphoedema	1	2	3	4	5	6
53	Coping with changes in your sexuality or sexual relationships	1	2	3	4	5	6
54	To be given information about problems with sexual relationships that may arise because of the lymphoedema	1	2	3	4	5	6
55	Dealing with loss of libido due to lymphoedema	1	2	3	4	5	6
56	Availability and variety of garments required for treatment of lymphoedema	1	2	3	4	5	6
57	Coping with problems with garments required for treatment of lymphoedema	1	2	3	4	5	6
58	Wanting more information about finding garments and other treatment needs for lymphoedema	1	2	3	4	5	6
59	Dealing with concerns about your financial situation because of the costs involved with lymphoedema	1	2	3	4	5	6
60	Non recognition or coverage of lymphoedema by Medicare or private health insurance	1	2	3	4	5	6
61	Other issues: please specify	1	2	3	4	5	6
62	Other issues: please specify	1	2	3	4	5	6

GENERAL BACKGROUND

We would like to ask some questions about you to help us group your answers.
Please put a circle around the number that best describes you.

63 Which hand do you normally write with?

Left	1
Right	2

64 Which arm is affected by lymphoedema?

Left	1
Right	2
Both	3

65 When were you first told of your cancer?

Less than 3 years ago	1
3-5 years ago	2
More than 5 years ago	3
Can't remember	4

66 When did you first notice your lymphoedema?

Less than 3 months ago	1
About 3-6 months ago	2
About 6-12 months ago	3
About 1-2 years ago	4
More than 2 years ago	5

67 In your opinion, did something happen that triggered your lymphoedema? If so, please state what happened in the space provided.

No	1
Yes	2

68 Have you used any of the following treatments for your cancer or related symptoms in the last 12 months? (Please circle)

	yes
Aromatherapy	1
Cellular therapy	2
Coffee enemas	3
Gerson diet	4
Herbal treatments	5
Homeopathy	6
Immune enhancing therapy	7
Iscador (Mistletoe)	8
Macrobiotic diets	9
Microwave or Tronado therapy	10
Naturopathy	11
Ozone therapy	12
Psychic surgery	13
Psychological therapy	14
Shark cartilage therapy	15
Other (specify.....)	16
None of the above	17

69 How old are you?

18-30 years	1
31-40 years	2
41-50 years	3
51-60 years	4
61-70 years	5
71-90 years	6

70 What is your present marital status?

Married	1
Defacto/ living with a partner	2
Separated/ divorced	3
Widowed	4
Never married/ single	5

Thank you for your participation

