

# Greater Boston Lymphedema Support Group Pump Survey

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This Pump Survey, conducted spring 1997, concerns both the short- and long-term results of pneumatic pump use in lymphedema cases within the Greater Boston Lymphedema Support Group. It includes a few cases in neighboring states.

The survey consisted of calling or trying to contact by mail the first 133 members of the group in the order of their signing up for our mailing list. No additional members were called after the first 100 persons had been interviewed. One additional person contacted us by herself. Twenty-eight members either did not return our calls or didn't respond to a mailing. Unfortunately, four members had died recently.

Thus, our sample group consists of 101 members. Due to the growth of our support group through connections to breast cancer support groups, breast care centers and medical fitting services, our membership is most likely over-represented in its cases of secondary arm lymphedema.

**TABLE 1: USE OF PUMPS IN SAMPLE GROUP**

56	had used a pump for some time
3	had used a pump for a week or less
42	had never used a pump.
TOTAL 101 members	
<i>The 56 members who used a pump for some time showed the following distribution according to their type of lymphedema: Primary leg(s), 10; secondary leg(s), 13; and secondary arm(s), 33.</i>	

**TABLE 2: BRAND OF PUMPS**

<u>Brand of pneumatic pump used</u>	<u>No. of members</u>
Lymphapress, various models	26
Jobst, one and more chambers	9
Biocompression, Sequential Circulator	7
Huntleigh Flowtron	2
Huntleigh Flowplus	1
Huntleigh Flowpress	1
Talley Multicom	1
Talley Hemaflow	1
Advantage	1
TOTAL MEMBERS	49
<i>49 members knew what brand of pump they had used, 7 member did not.</i>	

**TABLE 3: DURATION OF USAGE**

<u>Duration of pump use</u>	<u>No. of members</u>
10 - years	4
5 - 10 years	6
1 - 5 years	11
½ - 1 year	12
3 - 6 months	9
less than 3 months	11
TOTAL MEMBERS	53
<i>3 members did not state or did not remember duration.</i>	

**TABLE 4: RECOMMENDED PRESSURE SETTING**

<u>Pressure setting in mm Hg</u>	<u>No. of members</u>
Below 25	1
25 - 35	3
35 - 40	2
40 - 50	5
50 - 75	9
75 - 100	8
100 - 120	2
As high as possible	6
As painful as could be tolerated	1
<i>Not all members questioned remembered their settings</i>	

**TABLE 5: RESULTS OF PUMPING  
AS DESCRIBED BY MEMBERS:**

<u>Reduction of limb size</u>	<u>No. of members</u>
No reduction in size of limb, "pump doing nothing"	13
Slight reduction	2
Some reduction initially, "Not helping anymore"	7
Some reduction	4
Good reduction	6
Results short-lived	4
"Always use it before being fitted for new pair of support stockings"	1
<b><u>Positive results affecting pain, pressure and skin texture</u></b>	
Pain or pressure lessened	5
Skin after pumping better, softer	3
<b><u>Negative results of pumping</u></b>	
Limb showed increased swelling	2
Swelling pushed into back, thigh, abdomen, upper arm, chest or hand	8
"Made swelling worse under arm and side of breast"	1
More pain, soreness, feeling bruised	9
Cellulitis, infection in limb	2
"Caused hematoma"	1
"Hand got worse"	1
"Leg turns ice cold and numb"	1
"Lack of function in arm"	1
"Caused leaking in groin"	1
"Fibrosis in forearm may be due to pumping"	1
"My foot got sore, at the end of scar very sore and red"	1
<b><u>Impact on Lifestyle</u></b>	
Too time-consuming, "Hated sitting there"	5
Too tedious	1
"Isolated me because pump is too noisy"	1
"Didn't like being hooked / married to it"	1
<i>The same member may be listed several times under different headings, depending on the specificity of his/her statements. Not everyone described results of pumping in the same terms. In 3 cases a P.T. did treatments in addition to pumping.</i>	

**TABLE 6: REASONS FOR DISCONTINUING PUMP USE**

	No. of members
"Doctor saw that it didn't do what he expected"	1
"Doctor recommended not to use pump anymore"	1
"Doctor said pump (one chamber) was useless"	1
"Pump didn't do more than elevating legs at night"	1
"Stopped pumping when I started swimming regularly"	1
"Reading (about effects of pump) in literature made me nervous"	1
"Sleeve didn't fit right"	1
"Heard that liquid had no place to go"	1
Information from NLN	2
Heard from other LSG members about possible damage	3
Negative impact on lifestyle	7
Negative effects caused by pumping	22

*The negative results of pumping shown in Table 5 played a large role in the decision by members not to continue using a pump, in addition to the above remarks made during survey.*

**TABLE 7: DURATION OF PUMP USAGE VS. CONTINUATION OF USE & REPORTED DAMAGE**

Duration Of use	No. of Members	Members still using pump	Members who reported damage
10 – 20 yrs.	4	3	1
5 – 10 yrs.	6	1	2
1 – 5 yrs.	11	3	3
½ – 1 yr.	12	2	4
3 – 6 mo.	9	0	6
Less than 3 mo.	11	1	4
Not stated	3		
<b>TOTAL</b>	<b>56</b>	<b>10</b>	<b>20</b>

*Quite a number of members have tried a pump for less than a year. Of these, only 3 are still using a pump and 14 reported damages. On the other hand, in the group that has used a pump for more than a year, 7 members are continuing to use a pump and proportionally less damages were reported.*

Of the 56 members having used a pump for some time, 43 are not using a pump at this time. In three cases, it isn't clearly established whether a pump is still being used, and only 10 members are still using a pump (5 Lymphapress, 2 Biocompression/Sequential circulator, 2 Huntleigh Flowtron (3 chambers), and 1 Jobst (3 chambers). Twenty-five members last used a pump a year or more ago. Four are offering their pumps for sale; one member is looking for a pump. Distribution of pump brands more or less mirrors the distribution in the overall sample (Table 2).

Three of the continuing pump users, all with primary lymphedema and all using a Lymphapress, have used their pump for 10 years or more. However, one of these members uses the pump only sporadically before being fitted for the next pair of compression stockings. The other used to pump at 75–100 mm/Hg but is now pumping at 50 mm/Hg; she used to pump daily, two hours a day. Initially it helped with the pressure, made her legs feel less tired. Two years ago the legs got worse. She is now pumping three times a week but has no major reduction. The third member was told to pump at a

pressure setting as high as she could stand it. She pumped during the first year twice daily for 1–2 hours. Her leg went down but only temporarily. Now she pumps about once a month and the pumping shows less results.

Three of the continuing pump users have used their pump from two to five years. One uses her pump at the low setting of 25 mm/Hg, up to two or three times a week. Another uses it at 40–45 mm/Hg, four or five times a week, one to five hours per night, with good results. Her arms are nearly equal in size. The third one at first used the pump every night, at 70–80 mm/Hg, now uses it only when leg hurts, for ½ to one hour. The leg doesn't go down as much anymore, but the pumping still helps to relieve the pressure. The fourth one has used the pump since summer 1995. Using it for one hour brings the arm down. If she uses the pump every day, half an hour of pumping is enough to bring it down. Her arm is slimmer.

The remaining three continuing pump users have started to use a pump only recently: November 1996, October 1996 and February 1997. One has used it at 40 mm/Hg in conjunction with treatments by a physical therapist. She has not used it often, but expects to use it more during the hot weather. Pumping results in reduction in size and softer skin. The second one had used the pump for only a month, five times a week, two hours a day. The oncologist recommended pressure of 40 mm/Hg; the fitter recommended 50 mm/Hg. The pumping reduced her arm by one size regarding her compression sleeve. The last one was advised to pump at 100 mm/Hg. He is pumping daily, three to four hours a day with very good results: reduced volume, better skin condition, less pain.

**Conclusions:** Out of the 56 members of our support group who had used a pump for some time, 43 members are not using the pump anymore, and 25 of those haven't used their pump for one year or longer. The most frequently voiced reasons for discontinuing are that the pump "is doing nothing," "not helping anymore," that it has caused various negative results like swelling in adjacent area, pain and soreness. It seems that some members initially experienced good results, reduction, less pain and less discomfort. For the majority of the members, however, pumping delivered too many negative results after a while and they stopped using their pumps.

This survey is far from being a rigorous study. To draw far-reaching conclusions, more patients would have to be interviewed. In addition, the Greater Boston Lymphedema Support Group has a bias towards secondary arm lymphedema. The survey may have an additional bias in that especially patients who were discontent with the results of pumping may have looked for support within our group. It would be interesting to pursue these questions on a larger scale and in different populations. Nevertheless, the large number of negative results should warn any lymphedema patient of the potential for negative effects when using a pneumatic pump.

**References:**

Robert Lerner, MD, FACS: Problems with Pneumatic Pumps, Lymphedema Services P.C. Newsletter, Vol. 3, No.1, August 1995.  
 Christos J. Pappas, MD and Thomas F. O'Donnell, Jr., MD, FACS: Long-term results of compression treatment for lymphedema. Journal of Vascular Surgery Vol.16, no. 4, October 1992, p.555-564.