

# EXPERIENCES OF PATIENTS WITH LYMPHOEDEMA

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## Abstract

**Background:** The LSN and CRICP are working with the Lymphoedema Framework Project to develop a rational system for the delivery of lymphoedema care. **Aims:** To obtain an overview of patients' experiences and views throughout the UK. **Methods:** A questionnaire was sent to all members of the LSN. **Results:** A total of 1,449 responses were given, this being nearly 60% of the membership. Three-fifths of patients with a history of cancer said they had not been warned that they might develop lymphoedema. Half the respondents were dissatisfied with the help they had at first consultation about their swelling. Patients with cancer were more likely to have ongoing monitoring of their lymphoedema (79% vs 57% of non-cancer patients). Nearly 90% of all respondents had used compression garments. Manual lymphatic drainage (MLD) was used by 47% of cancer patients and 36% of non-cancer patients, and multi-layer bandaging had been used by one-third of respondents. Half the respondents had had at least one episode of cellulitis. Swelling adversely affected the daily lives of three-quarters of the respondents, including social activities, restrictions on clothing and footwear, social and psychological effects on confidence and body image, and the pain and discomfort they experienced. **Conclusion:** This study has highlighted the deficits in the care of patients with lymphoedema.

## Key words

Lymphoedema  
Survey  
Patients' experiences  
Healthcare deficits

Lymphoedema is a chronic swelling arising from accumulation of fluid and other tissue elements that would otherwise drain via the lymphatic system. It can be a grossly disfiguring condition, usually affecting a limb, which causes discomfort and may cause pain, and can be complicated by recurrent infections often requiring hospital admission (Badger et al, 2004a). Untreated, limbs can become huge, and the term elephantiasis illuminates

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their appearance. Sufferers report the psychological impact of the condition to be considerable (Williams et al, 2004; Morgan et al, 2005a). Causes include: cancer treatment; parasitic infection; and congenital problems in the development of the lymphatic system. In addition, lymphoedema frequently occurs in patients with other chronic diseases, such as spina bifida, rheumatoid arthritis and stroke. A recent study has revealed that there are at least 100,000 people suffering from lymphoedema in the UK alone (Moffatt et al, 2003).

The emphasis of treatment is on helping the patient to achieve as much self-sufficiency and independence as possible, given the chronic nature of their condition, and to reduce the incidence of co-morbidity and the need for intensive therapy and hospitalisation. Treatment may involve an intensive phase — decongestive lymphatic therapy (DLT) — that reduces the oedema. Methods include appropriate skin care, manual lymphatic drainage (MLD), multi-layer lymphoedema bandaging (MLLB), and isotonic exercise, though there is a dearth of

trial evidence to support the use of any of the physical therapies (Badger et al, 2004b).

The second phase of maintenance therapy may include self-bandaging, compression hosiery, exercise regimens, skin care and self-administered massage/simple lymphatic drainage. Surgery is rare and no effective drug treatment exists (Badger et al, 2004c).

The Lymphoedema Support Network (LSN) ([www.lymphoedema.org/lsn](http://www.lymphoedema.org/lsn)) was formed in 1991 as a national, patient-led organisation offering information and support to people with lymphoedema. It works to publicise the condition and campaigns for improved services. It takes a leading role in educating and supporting other patients with lymphoedema by providing a high standard of information and promoting self-help. The charity also aims to promote better awareness of lymphoedema as a major health condition to local health authorities, healthcare professionals and politicians, and campaigns for better national standards of care.

The LSN is currently working with the Centre for Research and Implementation of Clinical Practice (CRICP) at Thames Valley University on the Lymphoedema Framework Project (LFP) to develop a rational system for the delivery of care to patients with lymphoedema according to need (Morgan et al, 2005). As part of this project, a postal survey was sent to LSN members to obtain an overview of patients' experiences and views throughout the country. The topics addressed include the experience of living with lymphoedema, initial consultations with healthcare professionals, and the services and treatments used.

### Results

Questionnaires were sent to all members of the LSN in March 2003. There were 1,449 responses, representing about 60% of the membership at that time. Respondents were mainly from middle-aged and older groups: four out of five respondents were 50 years of age or older. Females predominated, as they do in many support groups: there were nine women respondents to each man.

Comparisons of LSN members with the wider population of lymphoedema patients are limited because so little is known of the national prevalence. An epidemiology study in south-west

London (Moffatt et al, 2003) had a higher proportion of men and more people of pensionable age (Table 1).

### Association with history of cancer

Nearly three-fifths (58%) of the LSN respondents had a history of cancer related to their swelling. The fact that LSN members include a disproportionately high number of people with a history of cancer, 58% compared with an estimated 25% in the population of lymphoedema patients (Moffatt et al, 2003), indicates the relatively greater awareness of the condition among cancer patients and the professionals with whom they are in contact. For this paper, people whose lymphoedema was related to cancer treatment are referred to as cancer patients. This group was predominantly female and over 50 years, with two-thirds having swelling of the arm or hand.

People with primary or non-cancer-related lymphoedema had generally had their swelling for much longer — 43% for more than 20 years. A large majority (86%) had swellings in the legs or feet only. This group will be referred to as non-cancer patients.

### Information about lymphoedema

Former cancer patients differed from non-cancer lymphoedema patients in their experiences of discovering their lymphoedema and seeking treatment.

In all, 31% of the respondents with a non-cancer-related swelling knew another family member with a swelling, compared with just 6% of those with cancer-related swellings.

For cancer patients, only 39% with cancer-related lymphoedema remembered that they had been told that lymphoedema could result from their cancer treatment. It appeared that there had been some improvement in the provision of this information in recent years. Even so, only half of the cancer patients whose swelling developed in the past five years had been warned about it, compared with one-third of those who had had swellings between five and ten years, and only one-sixth of those whose swelling developed more than ten years ago. Cancer patients should also be warned about the risk of having injections, or sustaining injuries, on an 'at-risk' limb, though only 65% said they were told about this. Such warnings were also recalled more by people whose swelling developed in the past ten years (71%), compared with those whose swelling was of more than ten years duration (56%).

### Access to treatment

Many patients who had had cancer were still in touch with oncology services when they developed a swelling, and a majority consulted a nurse, hospital doctor, or other healthcare professional about it in the first instance. Almost all (90%) of the people with non-cancer-related lymphoedema went to their GP in the first instance. The crucial role of the GP in the early diagnosis and treatment stages is underlined by the fact that even among people with a history of cancer, 39% consulted their GP first when they became concerned about their swelling. Only half of the respondents were satisfied with the help that they received at their first consultation. The proportion satisfied, or partly satisfied, was lowest for those consulting GPs first (38%), and highest (77%) for those consulting a nurse, including breast care nurses.

Overall, LSN members surveyed tended to be dissatisfied with their

**Table 1**

### Characteristics of LSN respondents and of general lymphoedema population

	LSN survey	Epidemiology study
<b>Age groups</b>		
Under 45 years	14%	10%
45–64 years	47%	56%
65 and older	39%	56%
<b>Gender</b>		
Male	9%	17%
Female	91%	83%
<i>n</i> = 100%	1,449	823

management. Non-cancer patients were much less likely to say they were satisfied with the help they got from the professional they consulted first — 26% were satisfied (and 5% partly satisfied) — than were cancer patients, of whom 59% were satisfied (and 4% partly satisfied). There were a variety of reasons for dissatisfaction, such as: 'being told to live with it'; inadequate information; initial misdiagnosis or no diagnosis; and lack of treatment.

Patients generally wanted to discuss their condition with someone they saw as knowledgeable about it. Satisfaction with the help they got from their GP was much greater when the GP had referred them to someone else (53% vs 16% when they were not referred on). In fact, GPs did refer nearly two-thirds (64%) of their cancer patients and just over half (54%) of their non-cancer patients. This difference again shows the relatively disadvantaged position of many non-cancer patients whose GPs may not have known where to refer them, or did not recognise there would be any benefit in doing so.

**Access to a lymphoedema specialist**

Despite the difference in GPs' referral rates for cancer and non-cancer patients at the first consultation, two-thirds of both groups of patients told us they had been assessed by a lymphoedema specialist at some time. But when they were asked whether their lymphoedema was currently being monitored, the picture was different for cancer and non-cancer patients. Significantly more of the cancer patients had regular appointments with a healthcare professional to monitor their condition (79% vs 57%), while more non-cancer patients were neither assessed nor monitored (25% vs 12%).

**Cellulitis (acute inflammatory episodes)**

An attack of cellulitis can be a frightening and extremely painful experience, which may require hospital admission and can lead to a worsening of the lymphoedema swelling. Half the respondents had experienced cellulitis, the proportion rising with the duration of the lymphoedema (Table 2). More

men, and more people with non-cancer lymphoedema, had had attacks of cellulitis than those with a cancer history. People with swellings only in the arm or hand were less likely to report experience of cellulitis than those with swellings in the leg or elsewhere.

The experience of an episode of cellulitis affected people's feelings about their lymphoedema. When asked whether their condition affected their daily living, respondents who had had cellulitis more often said it did (79% compared with 70% of those who had never experienced cellulitis). One-third of those who had had cellulitis had been admitted to hospital on at least one occasion because of it. Among non-cancer patients, having cellulitis led to a greater chance of being monitored (62% vs 50% of those who had never had cellulitis). Despite the high risk of recurrence of cellulitis, fewer of these patients were being monitored than were the cancer-related patients.

People with a history of cancer, whether they had had cellulitis or not, were significantly more likely than non-cancer patients to report they were being monitored (Table 3).

**Treatment received**

We asked all respondents to tell us what treatments they had used, whether they found them beneficial, and how

they were funded. Differences were apparent between cancer patients and non-cancer patients, and between patients who had been assessed by a specialist and those who had not. Table 4 shows the proportions that had used different treatments.

Compression garments had been used by the great majority (88%) of respondents, with little difference in the proportions of cancer and non-cancer patients who had used them. Funding was a somewhat different matter. Although the majority of garments were supplied and paid for by the NHS, 30% of non-cancer patients and 22% of cancer patients had to find other sources of funding, or paid for their own garments.

People with a history of cancer were more likely to have received manual lymphatic drainage (MLD) (47% vs 36%). In addition to this treatment being used more by cancer patients, it was funded by the NHS for a higher proportion of cancer patient users than for non-cancer patients. One in four cancer patients accessed NHS funding for some MLD treatment, while only one in six non-cancer patients managed to do this. Compression pumps had been used only by a minority of all patients, but more of the non-cancer lymphoedema patients had used one than had patients with a history of cancer.

**Table 2**

**Characteristics of respondents who have experienced an episode of cellulitis**

	Cellulitis	No cellulitis	n(=100%)
Male	62%	38%	133
Female	48%	52%	1270
Cancer history	41%	59%	822
No cancer history	61%	39%	591
Swelling in leg only	58%	42%	702
Swelling in arm only	37%	63%	535
Swelling in arm and leg	64%	36%	44
Torso affected	54%	46%	151
<b>Duration of swelling</b>			
< 10 years	39%	61%	870
> 10 years	66%	34%	566

Table 3

## Monitoring of patients who had experienced cellulitis

	Monitored regularly	Not monitored	n(=100%)
<b>Cancer-related lymphoedema</b>			
• had cellulitis	80%	20%	334
• no cellulitis	79%	21%	478
<b>Non-cancer lymphoedema</b>			
• had cellulitis	62%	38%	355
• no cellulitis	50%	50%	228

Table 4

## Treatments used by cancer and non-cancer patients, and by patients assessed and not assessed by lymphoedema specialists

Treatment used	Cancer patients	Non-cancer patients	Assessed by specialist	Not assessed by specialist
Compression garments	90%	87%	92%	82%
Manual lymphatic drainage	47%	36%	48%	32%
Multi-layer bandaging	32%	34%	39%	22%
Compression pump	14%	29%	23%	16%
Simple lymphatic drainage	66%	36%	57%	47%
Exercises	71%	41%	63%	50%
Skin care	75%	61%	73%	61%
Total (n=100%)	828	583	928	461

More than two-thirds of the cancer patients had practised simple lymphatic drainage (SLD) themselves, and/or done exercises, and/or practised skin care at some time. Smaller proportions of non-cancer patients used these treatments, but those who had been seen by a lymphoedema specialist did undertake them more than other non-cancer patients, probably due to individual tuition.

#### Views on treatments

More than four-fifths believed that compression garments (86%), MLD (81%), multi-layer bandaging (81%) and

skin care (87%) had benefited them. They were somewhat less convinced about self-massage SLD (63%) and exercises (70%), though there were still about two-thirds of users who thought them beneficial. Compression pumps had not been widely used (only 20% of respondents), and only one-third of those (33%) who had used pumps believed they had been of benefit.

#### Compression garments

Most of the respondents had worn compression garments. Patients with upper limb swellings were the most likely to have used garments (94% vs

87% for lower limb). People with more complex lymphoedema involving the torso or both upper and lower limbs, were least likely to have used garments, though the proportions who did use compression remained high (75%).

In all, 587 respondents had used upper limb garments (sleeves, gloves and mittens), and 752 people had used garments for lower limbs (stockings, tights and toe gloves). One-quarter of garment users said they had had a garment specially made for them at some time. Garments were supplied for two-thirds (66%) of users by a lymphoedema clinic. The figures were higher for cancer patients: 75% were supplied by a lymphoedema clinic, compared with 51% of non-cancer patients. People who had their garments from a lymphoedema clinic were more likely to obtain a replacement garment at least every six months: 87% said this vs 81% of those who obtained their garments elsewhere.

Twenty-one per cent got their garments through a hospital surgical appliance department, and 7% from their GP. Relatively more of the latter were non-cancer patients and lower limb garment users. Only 4% of people ordered their own (mostly lower-limb garments) directly. One-third of users had paid for their own garments at some time. This was partly because they had no other choice, but some stated that they wanted more garments than were supplied. Most users (81%) said they wore their garments every day. A further 10% wore them at least five days a week. Very few had ever hoped that wearing the garment would cure their condition, but half said they had expected it to reduce the swelling. More of those wearing sleeves and gloves expected a reduction in swelling (59%) than those using stockings and tights (44%). The other main expectation, of two-fifths of all users, was that the garment would control the swelling and prevent it getting worse. When asked about the success of the garments, 86% said they had been successful, or fairly successful. This is consistent with the replies to a previous question, where 86% of users thought their garments had benefited them.

There was no difference in responses between groups relating to the success of upper or lower limb garments. Although still a minority, rather more women than men were disappointed: 15% of female respondents said their garment had been unsuccessful or fairly unsuccessful, compared with 5% of males. About one in seven respondents who had used a garment, had stopped wearing it by the time of the survey. The most common reason for giving up, given by 26% of former users, was an increase in pain or discomfort. Others, particularly lower-limb garment users, had given up because of problems with the fit. Fifteen per cent said they felt it was of no benefit, and 13% said their swelling had reduced and the garment was no longer needed. Other reasons given for stopping were that it had caused swelling around the garment, affected the skin or was intolerable in hot weather.

Problems were also encountered by many of those who were able to continue wearing their garments. Patients found putting on and removing a leg garment was more problematic than for those with a sleeve (43% vs 29%). A similar proportion experienced swelling above or below the garment (27% sleeve vs 24% stocking). Skin irritation was experienced by 18% of sleeve wearers, compared with 13% of stocking wearers. When asked to sum up how they felt about their garment, 42% said they were pleased with their garment and felt comfortable with it. However, a considerable minority of users (22%) expressed very negative feelings about the garment, such as feeling resentful or depressed. About one-third (36%) said they had got used to living with it as 'a necessary evil'. Women were twice as likely as men to express negative feelings about their garment (23% vs 11%).

More than half the users felt the garment affected their daily life by limiting their choice of clothing or footwear; by restricting their activities; because it was unsightly, or because it took a great deal of time to put on

and take off every day. Respondents were asked what they were looking for in a garment. The characteristics most frequently required by respondents were that it should be comfortable, supportive, and a good fit (59%). Additional comments were that it should give strong, effective control of the swelling (44%), and that it should be attractive in colour and appearance (41%). Surprisingly, only 11% stated that it should be easy to put on or remove.

**How did lymphoedema affect people's lives?**

A series of open questions were asked about the effects of lymphoedema on daily living, work, social life, and close relationships (Table 5). Three-quarters of respondents said it did affect their daily living, particularly those who had swelling in their legs or torso, and those who had experienced cellulitis.

Functional difficulties with affected limbs, including general mobility, such as walking, bending (25%), and problems with lifting or using an arm (17%) were most frequently reported.

One in seven specifically mentioned the restrictions they experienced in the clothes and shoes they could wear (14%). Others spoke of problems doing housework (14%), or not being able to enjoy leisure activities such as gardening or writing letters (13%). Again, one in seven

said their lymphoedema affected their daily lives because of pain, aching or tiredness (13%).

Persistent tiredness, pain or aching was reported much more by people who had both an arm and a leg affected by lymphoedema, or those with swellings in the trunk, neck or head (24% vs 7% of those with arms affected only, and 14% of those with affected legs).

When asked about any effect on work, again more of those with leg swelling, than arm swelling, said their work was affected. The most common problems reported were with sitting or standing for long periods, and with manual dexterity using keyboards, or with handwriting. Those whose swelling involved the head or torso said their work was affected most of all. Social life was affected for more than half the respondents, again more so for those with swellings in lower limbs or torso. The reasons given were lack of confidence and feelings of self-consciousness, as well as restrictions on clothing and footwear. Social activities, particularly dancing, were impossible for some. Close relationships were affected for one in five of the respondents, with swellings of the torso and legs damaging self-confidence and inhibiting intimacy more than arm swelling. People aged between 30 and 49 years were more likely than older people to say their close relationships had been affected.

**Table 5**

**Percentages saying their swelling affected daily living, work, social life and close relationships**

	Daily living	Work	Social life	Close relationships
<b>Swelling in:</b>				
• arm/hand only	69%	41%	38%	12%
• leg/foot only	75%	53%	63%	25%
• arm and leg	89%	63%	67%	44%
• torso	88%	63%	66%	32%
All respondents	75%	42%	54%	21%

To try to establish what respondents perceived as their main problem, they were asked to sum up what bothered them most about the swelling. What seemed to bother more people than anything else were the restrictions caused by their swelling on the clothing and shoes they could wear (30%). Almost as frequently mentioned (28%) were feelings of self-consciousness and poor body image. Those with leg and/or torso swellings were more likely to say this than people whose arms only were affected. One in four respondents, particularly those with torso swellings, wrote about physical discomfort, heaviness or pain as their main problem. Other concerns, noted particularly by patients with arm swellings, were the unsightliness or discomfort of compression garments, or simply having to wear them. A number were most bothered about the permanence of the condition, and others that it would get worse or out of control. Just 1.5% said that nothing much bothered them about the swelling.

Finally, the respondents were asked for any suggestions for improving the services for people with lymphoedema. The most commonly given responses are shown in Table 6.

**Table 6**

**Suggestions for improvements to services**

- More resources 27%
- GPs (specifically) to be better informed 18%
- Healthcare professionals (generally) to be better informed 12%
- Better information for patients regarding condition and/or clinics 12%
- More funding/availability of MLD or bandaging 15%

n = 100% 1449

**Conclusion**

The responses of these LSN members showed that many patients had difficulty in obtaining a diagnosis and effective treatment. Healthcare professionals were often uninformed about lymphoedema, or did not know how to provide or access appropriate care for their patients. There were significant differences in the experiences of people whose lymphoedema was related to their history of cancer, when compared with other patients whose condition was of genetic origin, or had other, non cancer-related, causes.

**The case argued by the LSN for greater awareness of primary and secondary lymphoedema that is unrelated to cancer treatment, is supported by the difficulties in accessing services reported by the patients in this survey.**

The case argued by the LSN for greater awareness of primary and secondary lymphoedema that is unrelated to cancer treatment, is supported by the difficulties in accessing services reported by the patients in this survey. This included lower referral rates by GPs to lymphoedema specialists, less access and funding for MLD massage treatment, and lower rates of monitoring, even for those who had the serious — and costly — complication of cellulitis.

The Lymphoedema Framework Project is currently evaluating a new primary care model for lymphoedema in the Wandsworth Primary Care Trust supported by the King's Fund (Morgan et al, 2005b). The information from the survey reported here, and comparable data from interviews with patients in Wandsworth, will be used to give the patient's perspective. The results from the present survey have indicated some of the current deficiencies and how much needs to be achieved to

provide an appropriate and equitable service for all those affected by lymphoedema. **IL**

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**Key Points**

- » Lymphoedema affects many aspects of the patients' lives.
- » Patients find difficulty in obtaining a diagnosis or effective treatment.
- » Care of patients with lymphoedema is less than optimal for all patient groups.
- » Patients with cancer often receive better care than non-cancer patients.
- » GPs need to be better informed about the condition and access to care options.