

LYMPHOEDEMA SUPPORT NETWORK: A SHORT HISTORY

Anita Wallace

The Lymphoedema Support Network (LSN) is the only national patient-led organisation that supports people with lymphoedema by providing clear information about the condition and encouraging a nationwide network of support groups. From its beginnings in 1991, it has fought to raise awareness of the condition in parliament, in hospitals and in primary care. It remains committed to improving accessibility to treatment, and to raising the standards of care for patients by campaigning for better national resources to be invested in lymphoedema management.

Key Words

Lymphoedema
Support Network (LSN)
Raising awareness
Patient support
PCT campaign
Self-help

The Lymphoedema Support Network (LSN) is the only national patient-led organisation that offers information and support to people with this condition and it has a unique understanding of the patient's experience. Since its inception in 1991, when there was very little information or help available for patients, the LSN has evolved into an independent and influential charity. It takes the lead role in educating and supporting patients with this condition by providing a high standard of information and promoting self-help. It also aims to promote better awareness of lymphoedema to local health authorities, healthcare professionals and politicians, and campaigns for better national standards of care.

The LSN began as a small patient support group with the help and

Anita Wallace is Chair of the Lymphoedema Support Network, St Luke's Crypt, Sydney Street, London

guidance of two lymphoedema nurses at The Royal Marsden Hospital in Chelsea, London. A desk and a filing cabinet in the Royal Marsden's appeal office became the LSN's first headquarters. By February 1993, the LSN received charitable status and in May 1993, with 150 members, it held its first annual general meeting and published its first newsletter.

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In 1994, the LSN produced a pamphlet describing lymphoedema, and giving useful information for patients. This leaflet was also included in an information pack for nurses and healthcare workers who had requested information on setting up local support groups (of which there were then seven).

By May 1995, the membership had grown to 530 and links had been established with organisations in the UK, Australia and the USA. The results of a 1995 patient questionnaire indicated that 89% of the respondents felt the

LSN had been successful in helping them, and 50% felt the LSN had managed to raise the awareness of lymphoedema generally and had given them information about the condition. The LSN also asked its members what more it should be doing. Responses indicated that the charity should try to raise its profile with more publicity; make GPs more aware of the condition; lobby for treatment and manual lymphatic drainage (MLD) therapy to be available on the NHS, and to actively establish more local support groups. These suggestions became the basis for the charity's aims and objectives, which are:

- ▶▶ To provide support for people with lymphoedema
- ▶▶ To provide information about lymphoedema and its treatment
- ▶▶ To work towards the availability of better national resources for lymphoedema treatment
- ▶▶ To maintain contact with healthcare professionals working in lymphoedema management
- ▶▶ To promote a network of support groups throughout the UK for people with lymphoedema.

In 1996, the LSN moved into new offices in the crypt of St Luke's Church, Chelsea and employed a part-time, paid administrator. The first National Lottery application for core funding was submitted, but this was unsuccessful. However, despite very limited resources, the LSN's fundraising events enabled

it to keep the office going while the committee continued to work on other funding applications. Thanks to industry sponsorship, a general information leaflet and poster were produced and members were encouraged to provide GPs with information about the charity in an attempt to raise awareness of the condition. Several articles appeared in the national press, leading to increased interest and a boost to the membership figures.

By the summer of 1997, the number of support groups in the UK had risen to 24, the LSN had 854 members and what was believed to be the only national database of people with lymphoedema. Approximately one-third of the membership had primary lymphoedema. The LSN was aware that the few services available for these patients were under threat and it is a sad reflection that, nearly a decade later, the situation for so many patients remains the same.

The LSN continued to be short-handed and actively sought new trustees and volunteers, who could bring additional skills to assist with the increasing demand for its services. Although there was more public awareness of lymphoedema, the impact of the condition on daily life, particularly when untreated, was still not appreciated by many medical practitioners. This left patients in desperate need of the support that the LSN could offer.

The charity continued to go from strength to strength. In 1999 the membership continued to increase steadily and 37 support groups had been established. New computers greatly assisted in the efficient running of the office, a website was set up and plans were in progress to develop a comprehensive information resource for lymphoedema in the UK. The charity's newsletter, *LymphLine*, was now produced quarterly and the sale of LSN Christmas cards was introduced. It was also encouraging to note that while working on a stand at the GP conference in 1999, LSN representatives found there was a much greater interest in lymphoedema than had been

experienced in previous years. The message was reaching its audience.

Self-help videos

A small team of dedicated volunteers were actively involved in the charity and this enabled the production of the LSN's first self-help video encouraging patient compliance. The video highlighted that by working together with a lymphoedema practitioner, there is much that patients can do to help themselves in the management of their own condition. This video (which is no longer available) demonstrated exercises and breathing techniques which were beneficial for all ages.

Following the success of its first self-help video, the LSN welcomed the opportunity in 2001 to work on a joint initiative with the Leeds Teaching Hospitals NHS Trust to produce two new self-help videos. The videos, primarily produced for patients, also proved to be a valuable resource and teaching aid for healthcare professionals, and they demonstrate techniques to help control lymphoedema of the arm and leg. Each video covered the self-management aspects of care,

including compression garments, skin care, exercise and the simple lymphatic drainage (SLD) technique.

Factsheets

Despite increased awareness of lymphoedema, the lack of written information available from the NHS for patients was still a major concern for the charity. However, thanks to generous donations, the LSN took on the role as an information provider and, together with the specialist help of experts in lymphoedema management, produced the LSN's first six factsheets. Peter Mortimer, the UK's leading lymphoedema authority, became the charity's chief medical adviser and has continued to provide his unstinting help and expertise for all the LSN's publications.

The charity is now the largest information resource for lymphoedema in the UK, continuing to produce an ongoing series of factsheets, initially for patients; however, the high standard of this information has led to healthcare professionals ordering them for use in hospitals, hospices and lymphoedema clinics. In 2005, the LSN received orders

Box 1

Comments from LSN members about the impact the network has had on their lives

'I have enjoyed both the video and the newsletters. I have had more benefit from them than from four consultants, who have just looked at my legs and said, primary lymphoedema, sorry, nothing but pain-killers and support tights.'

'I have picked up more advice in the past couple of weeks of becoming an LSN member than in the last two years since I developed lymphoedema.'

'As far as I can see, there isn't anyone in my area with any knowledge of lymphoedema. I've learnt all I know from the LSN and I have you to thank.'

'I learnt more from reading your information than I have learnt from my doctors.'

'I've only had three newsletters, but I was absolutely amazed at the number of fellow sufferers and several times I've been reduced to tears just to know someone out there is going through the same things I am.'

'I felt very isolated and depressed about the condition. Since joining the LSN and receiving *LymphLine*, all the articles, advice and the experiences of other sufferers have helped a great deal.'

'I find [the LSN] newsletter a great comfort in what can sometimes be a very lonely and frightening condition. It is truly an enlightening read, also informative, and without it, I feel I would have been forced to get on with it, and stumble aimlessly along with a painful and debilitating disease.'

for over 70 000 factsheets. Generally considered to be 'gold standard', the factsheets are written by healthcare professionals, with additional input from LSN trustees and members; and they are all reviewed by the charity's chief medical adviser before publication. Topics include 'Swollen feet', 'Coping with lymphoedema following a mastectomy or lumpectomy', 'Skin care', and 'Psychological and social aspects of lymphoedema'. The LSN's original six factsheets have now been revised and updated and there are currently 21 factsheets in the series.

Lobbying campaign

A turning point in the development of the charity occurred when the LSN welcomed its 2001st member in the year 2001; a 79-year-old woman who had suffered with lymphoedema for 46 years, but had only been diagnosed three years before while visiting a geriatric hospital. This appalling situation underlined the need for the LSN to increase its activities by developing a campaign and advocacy programme to highlight the desperate plight of thousands of patients in the UK.

With this in mind and with the help of a professional political lobbyist, the trustees began to prepare a strategy to lobby MPs in an attempt to increase awareness within the Government of the vital need for diagnosis of the condition, and a suitable level of care for all lymphoedema patients.

The fundamental objectives of the political campaign were to increase the awareness of lymphoedema in Westminster and Whitehall. In particular, the campaign highlighted:

- ▶▶ The need for a greater general awareness within the medical profession in terms of improved diagnosis and treatment
- ▶▶ The cost-effectiveness of professional management and the related cost savings, not just to the NHS but also to the national economy through a reduction in lost working hours and the cost of social security payments
- ▶▶ The need for increased resources to identify how many people suffer from lymphoedema in the UK

- ▶▶ The need to establish national standards of lymphoedema care and availability.

LSN members were encouraged to write to their local MPs using a draft letter produced by the charity, asking them to raise crucial issues with the Health Secretary such as levels of funding and availability of treatment. General briefing letters were also sent to all relevant ministers, officials and parliamentarians who had responsibilities, or a particular involvement in related policy areas.

The LSN is now the largest information resource for lymphoedema in the UK...In 2005, the LSN received orders for over 70,000 fact sheets.

The charity launched its political lobbying campaign in Autumn 2001 and, as a direct result, an adjournment debate on 'The treatment of lymphoedema' was delivered in the Westminster Hall debating chamber on 10 December 2002. This was the first ever formal mention of lymphoedema in a House of Commons debate. The lobbying campaign continued to generate great interest and support. Several written questions regarding lymphoedema were subsequently tabled in the House of Commons; however, responses from health ministers were less than satisfactory as they focused entirely on patients with breast cancer.

More recently, the levels of awareness and understanding of lymphoedema within both Westminster and Whitehall have slowly but steadily increased. Six early day motions (EDMs) have now been tabled by MPs on behalf of the charity, all of which gained full cross-party support. Several MPs are now actively engaged in pursuing the issues surrounding lymphoedema on behalf of their constituents, and many MPs have congratulated the LSN on its campaign strategy. The most recent EDM, tabled in 2005, stated 'that this House pays tribute to the work of the LSN in

raising the profile of the desperate plight of thousands of sufferers in the UK... and calls upon the Government to work closely with the LSN to ensure sufferers are able to access readily all necessary prescribed treatments'. This campaign is ongoing and the LSN will continue to lobby parliament.

10th anniversary

When the LSN celebrated its 10th anniversary in December 2001, the charity hosted a reception at the Royal Marsden Hospital and received tributes from both members and healthcare professionals regarding its many achievements. Professor Mortimer commented that he continued to be 'knocked out' by the LSN's work. However, it was not all plain sailing, as news had recently been received that the LSN's second attempt to secure Lottery funding had been rejected. The charity still desperately needed the funding to implement its many and varied plans and projects.

National lymphoedema framework project

Undaunted, the LSN became a full research partner in the national Lymphoedema Framework Project (LFP). The charity was delighted to be given this opportunity to work with Christine Moffatt and Peter Franks towards improved service provision for lymphoedema patients.

As part of its work within this project, the LSN subsequently developed a questionnaire to gauge the patient's experience which was sent out to its membership in March 2003. The analysis of 1400 questionnaires was carried out at the Centre for Research and Implementation of Clinical Practice (CRICP). The findings, regarding the particular difficulties that primary lymphoedema patients experience in accessing treatment, confirmed what was already known. This information will be used to further enable the LSN to highlight the problems that lymphoedema patients encounter.

Other organisations

The trustees continued to build on relationships with other organisations and currently work closely with the

British Lymphology Society (BLS), regularly holding joint meetings. The LSN also attends the BLS annual conference, which gives an excellent opportunity to network with many healthcare professionals. Close links are also maintained with MLD^{UK}, the association for manual lymphatic drainage practitioners.

The charity is an active member of the Long-term Medical Conditions Alliance (LMCA), the umbrella body for national voluntary organisations working to meet the needs of people with long-term health conditions. The LSN has also developed links with many of the major charities including, Breast Cancer Care, Breakthrough Breast Cancer, Breast Cancer Campaign, Macmillan Cancer Support and Cancer Backup.

PCT campaign

It became clear during the LSN's political campaign that it needed to extend its campaign and advocacy programme to include all primary care trusts (PCTs) and strategic health authorities (SHAs). This became apparent from letters received by LSN members from their MPs, which included correspondence from the Department of Health stating that, 'It is

Key Points

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- ▶▶ The LSN has grown steadily since 1991, and now has a membership of more than 3500 patients, healthcare professionals and others concerned with lymphoedema management.
- ▶▶ The LSN has helped many thousands of patients and remains fully committed to providing information and support to people with lymphoedema, their carers and families.

the role of the PCTs to decide which services to provide for local people, including the prevention and treatment of lymphoedema. The local professionals in PCTs are best placed to understand local health needs and commission services to meet them.'

The LSN launched its new campaign in October 2004, targeting all PCTs and SHAs. The aim was to ensure that lymphoedema and its treatment is fully recognised and firmly placed on the local healthcare agenda.

The charity gained influential endorsement to this patient-led initiative from The Royal College of Physicians, The Royal College of General Practitioners, The Royal College of Nursing, Macmillan Cancer Relief, Breakthrough Breast Cancer, The Association of Chartered Physiotherapists in Oncology and Palliative Care, LMCA and Nick Bosanquet, a health economist from Imperial College, London. Professors Mortimer, Moffatt and Franks, and the BLS also gave their full support.

- In particular, the LSN highlighted:
- ▶▶ How many people have primary and secondary lymphoedema
 - ▶▶ That increased government funding for the NHS is not reaching lymphoedema patients
 - ▶▶ The benefit of early diagnosis and appropriate treatment
 - ▶▶ The cost-effectiveness of professional management and the related cost savings
 - ▶▶ Quality of life issues for lymphoedema patients.

The campaign's initial phase included several elements:

A letter incorporating these issues was sent to each of the PCTs and SHAs, signed by the LSN chairperson and Professor Mortimer, together with a copy of the first NLFP journal which had published standards of practice for PCT-based lymphoedema services; the analysis of 1400 patient experience questionnaires, completed by LSN members, and the logos and quotes from supporting organisations.

LSN members and supporters also wrote to their local PCTs using a draft letter produced by the charity. The BLS sent a supporting letter to all PCTs and SHAs further highlighting the need for greater resources. A further letter was sent to the PCTs and SHAs in May 2005, together with a copy of an early day motion and a list of its signatories, to highlight the level of support gained from parliament. The issue of the discrimination between service provision for cancer-related and non-cancer-related lymphoedema patients was also strongly underlined.

- A brief summary of the replies subsequently received from PCTs by the LSN and its members indicated that some PCTs appeared to be more prepared to acknowledge the inadequacies of services in their area to patients, rather than to the LSN. Some PCTs were unaware of current services in their area and talked about services that no longer existed, and some PCTs referred to services that had never existed. Although others acknowledged there was no service provision within their trust, they did refer patients to services outside their area. However, there were some positive results:
- ▶▶ Seventeen PCTs agreed to take part in the NLFP
 - ▶▶ Some PCTs have developed new services, a number of which are being coordinated across more than one PCT
 - ▶▶ Several PCTs said local cancer networks are now undertaking mapping exercises to clarify the pattern of services used and to identify unfulfilled needs
 - ▶▶ Some are trying to develop new services and, although a number of these are initially only for cancer patients, they are hoping to extend these services to include non-cancer patients.

However, there is still a very long way to go and the LSN will continue to carry on raising the profile of the condition within PCTs. The LSN has subsequently extended its campaign to include the Scottish health boards and the local health boards in Wales.

Funding applications

The lack of statutory funding has long been an issue for the LSN, forcing the charity to rely on its £10 membership subscriptions and donations and to feel increasingly frustrated that it is unable to put some of its plans into action. With this in mind, the LSN trustees appointed a professional fundraiser to work with them on a new application to the Big Lottery Fund to help finance a major development project. The LSN has since been awarded £100 000. This funding has enabled it to appoint a full-time fundraising and development manager, who will assist the trustees in implementing a three-year development plan. This plan includes:

- ▶ Influencing long-term care policy and practice by targeting PCTs
- ▶ Instigating more media opportunities and raising awareness of the condition and the services the LSN can offer
- ▶ Reaching more patients — diagnosed and undiagnosed
- ▶ Reaching more lymphoedema services
- ▶ Targeting breast cancer clinics with literature about preventing lymphoedema
- ▶ Providing more information; in print, video and DVDs
- ▶ Launching further patient satisfaction questionnaires
- ▶ Translating resource materials for minority and ethnic groups
- ▶ Attending more conferences and exhibitions within the healthcare arena
- ▶ Taking part in the Expert Patient programme.

Much of this work is ongoing and is proceeding in many key areas. However, with the additional resources, the work has a more secure financial basis and will shorten the timescale considerably. It is a great achievement for the charity to be awarded this substantial grant, and it is the culmination of a tremendous amount of hard work and determination.

Cellulitis consensus document

One of the major concerns for people with lymphoedema is the risk of developing infection (cellulitis). Treatment of cellulitis in lymphoedema is very important. Patients need to

fully understand the risk factors, quickly recognise the onset of infection and know when to seek medical help. However, inappropriate prescribing of antibiotics by GPs has long been a major problem for some patients and can cause considerable distress and unnecessary suffering.

For far too long, lymphoedema has been sidelined by the medical profession and healthcare providers. The LSN will continue to work in whatever way it can towards ensuring that all patients in the UK receive an early diagnosis, equitable access to treatment, a suitable level of care, and improved quality of life.

With this in mind, the LSN coordinated a meeting between eminent lymphoedema specialists and other medics in order to gain an agreement on the appropriate management of cellulitis for lymphoedema patients. The outcome of this meeting was a consensus document that makes recommendations about the use of antibiotics in lymphoedema, and advises when admission to hospital may be indicated. This document is jointly owned by BLS/LSN and has formed the basis of a new LSN factsheet, 'Management of cellulitis in lymphoedema', which is aimed at doctors rather than the patient. The document is also available on the members-only section of the BLS website. An audit will take place to evaluate the effect of this information. It is hoped that, in the long-term, any problems that patients currently face will be greatly reduced.

Cancer campaigning group

Further recognition of the work of the LSN was recently acknowledged when it was invited to become a member of the Cancer Campaigning Group (CCG); a coalition of 28 cancer charities. The CCG represents cancer research, education and patient empowerment. In

coming together, the group has achieved a high profile as it focuses on ensuring that cancer remains a top priority at Westminster. The affiliation not only aims to highlight the progress being made in cancer services, but also to call for specific further actions that will benefit patients. The LSN is hopeful that by joining this influential coalition, it will be possible to further raise the political profile of lymphoedema.

Summary

The LSN has grown steadily since 1991, and now has a membership of more than 3500 people with lymphoedema, healthcare professionals and others concerned with the management of lymphoedema. There are now more than 60 local support groups throughout the UK and Ireland. The LSN has helped many thousands of patients and remains fully committed to providing information and support to people with lymphoedema, their carers and families.

Despite the LSN's commitment and hard work, it continues to receive numerous telephone calls, letters and emails from patients who experience difficulties in obtaining access to treatment. While parts of the country have very good lymphoedema clinics, in some areas services are limited in scope and are, in effect, rationed. In some places there are no lymphoedema clinics, or they are only available for patients who have lymphoedema following treatment for cancer. Therefore, patients with lymphoedema that is unrelated to cancer receive little or no help and are left to struggle in the community. It is important to note that less than half of all lymphoedema services in the UK are able to treat non-cancer-related patients; the LSN believes this is discrimination and encourages all healthcare providers to address this unacceptable situation.

For far too long, lymphoedema has been sidelined by the medical profession and healthcare providers. The LSN will continue to work in whatever way it can towards ensuring that all patients in the UK receive an early diagnosis, equitable access to treatment, a suitable level of care and improved quality of life. JL