

# The National Lymphoedema Framework project

**Phil Morgan, Christine Moffatt**

*Dr PA Morgan is Post-doctoral Research Fellow and Professor CJ Moffatt is Director, Centre for Research and Implementation of Clinical Practice, Thames Valley University, London*

*Email: phil.morgan@tvu.ac.uk*

The National Lymphoedema Framework (NLF) project is a partnership between the Centre for Research and Implementation of Clinical Practice (CRICP), the Lymphoedema Support Network (LSN) (the national patient support group), the British Lymphology Society and the wound care and compression industry.

The project originated from an epidemiological study undertaken in south-west London, which identified that lymphoedema is a significant but unrecognized problem (Moffatt et al, 2003). Major deficits in care were identified, with 36% of people receiving no treatment for their lymphoedema. The study also highlighted that for those who were receiving treatment, bandaging and manual lymphatic drainage (MLD) were infrequently used, patients were often unable to access necessary specialized lymphoedema garments and inappropriate treatment – such as the use of diuretics – was frequently prescribed.

In addition, the study indicated that care was mainly based on the underlying cause of the lymphoedema. Most services, and resources, were focused on cancer-related lymphoedema and carried out exclusively by specialist practitioners, often in hospital settings. This focus on hospital-based specialist provision often meant that patients reached a stage of complex lymphoedema before specialist treatment was made available. Equally, the centralization of care on a specialist service led to there being patients who, on clinical grounds, could have been discharged into the community had it not been for a lack of an appropriate structure to manage their lymphoedema in the community care setting. Indeed, there is considerable anecdotal evidence to suggest that the role of community nurses is increasingly concerned with managing some of the most complex cases in the patient's own homes on a day-to-day basis with little support. The converse of this was also true, with many people with lymphoedema remaining unrecognized.

In response to these findings, the NLF project has two related aims: The first is to support the development of integrated, primary care-based lymphoedema services that help ensure early recognition, appropriate treatment, ongoing care and access to specialist services when required, no matter what the cause of the lymphoedema. The second is to provide evidence, from data collected from participating primary care organizations,

that lymphoedema is a major problem, which is currently under-resourced and for which national guidance for management is required.

The main thrust of the NLF is, therefore, to implement an effective primary care-based lymphoedema service. This is being achieved by developing the skills and knowledge of existing community health-care practitioners such as GPs, practice nurses, district nurses and carers in social care settings to ensure the early recognition, treatment and then long-term management of patients with lymphoedema of all causes. Such an integrated, primary care-based, model will allow specialist lymphoedema services to be used more appropriately in dealing with complex cases and supporting community practitioners, particularly community nurses, in the long-term care of patients with lymphoedema.

## Progress of the project

With funding from the King's Fund, the NLF began in one primary care trust (PCT) in south-west London in February 2002. It has since been rolled out nationally with a number of PCTs across England taking part and others awaiting confirmation to join. The participating PCTs are currently implementing and evaluating PCT-based lymphoedema services based on national standards and a best practice document, both developed through a rigorous consensus process (Murphy et al, 1998). Data for the evaluation is collected using a customized software package, which incorporates questions relating to the use of the service as well as tools designed to evaluate outcomes such as the psychological burden of lymphoedema and health-related quality of life.

## ABSTRACT

Lymphoedema is a common but unrecognized problem. The National Lymphoedema Framework (NLF) – a partnership between academics, patients, lymphoedema specialists and industry – is working to implement a new approach to lymphoedema care to tackle this problem. This article discusses the progress of the NLF, and describes the role of community nurses in the new service framework.

## KEY WORDS

Lymphoedema ♦ National Lymphoedema Framework ♦ Community nurses ♦ Role

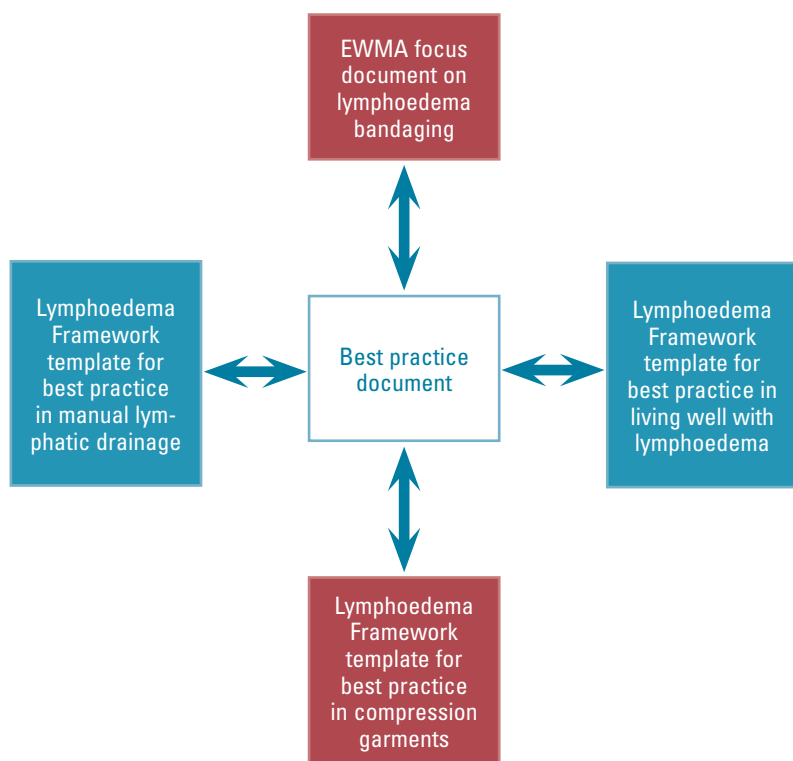


Figure 1. Hub-and-spoke framework of NLF resources. Red indicates published documents, blue indicates documents currently being prepared.

### Support for an integrated service

During the three years since the NLF was launched, there have been a number of developments aimed at supporting the integrated services developed by the participating PCTs. These developments can be divided broadly into four categories; education, published resources, policy change and new research.

#### Education

Education is key to building an effective integrated model of care. This is the case for all professionals involved and particularly so for community nurses. The central role of the community nurse in the long-term management of patients with lymphoedema has long been recognized, but also that this role requires both knowledge and skill (Badger, 1995). A study to assess the educational needs of community nurses regarding the management of patients with lymphoedema was carried out as part of the NLF in 2004. This showed that community nurses were concerned about their lack of knowledge and skill and also that there was considerable uncertainty regarding their role relative to other professionals involved in the care of these patients (Morgan et al, 2005).

These findings contributed to a number of educational courses specifically designed to prepare community nurses for their role within the NLF. The courses range from accredited 3-day, in-service, skills-based programmes for all community nurses, to level 6 academic modules in the management of patients with lymphoedema for those who wish to become key workers within the integrated service.

These programmes are in addition to already established educational programmes, including masters degree courses, that are available around the country.

#### Published resources

A number of documents have been published as part of the NLF. They are intended to provide health professionals with guidance on best practice in the management of people with lymphoedema, based on national and international consensus. These publications form a 'hub-and-spoke' resource framework (Figure 1). The hub is formed by the key NLF document, entitled *Best Practice for the management of people with lymphoedema in a primary care trust*. The aim of this document is to provide practical and accessible help to PCT staff who care for people with lymphoedema on a day-to-day basis in a community setting. An international version of this document is to be published this year.

Closely linked to this 'hub' document are four publications that focus on particular areas of practice in more depth. Two of these are currently in print – a European Wound Management Association focus document on lymphoedema bandaging (EWMA, 2006), currently available in three languages, and an NLF 'template for best practice' document on compression garments. The remaining two documents, which will be published over the next 2 years, will focus on MLD and living well with lymphoedema. All these documents have been endorsed by an international panel of experts and the international lymphoedema societies.

#### Policy change

A fundamental shift in policy that will have major beneficial implications for the management of lymphoedema in the community is the acceptance by the drug tariff of lymphoedema as a new, and separate, classification. One of the major barriers to moving an integrated PCT model of care forward has been the limited availability of compression garments designed specifically for lymphoedema rather than for venous disease. Furthermore, these garments, particularly those for the arm, were only available through the hospital system. A major focus of the NLF has therefore been to encourage and support the rethinking of the design of garments to form a new classification within the drug tariff based on European standards of compression for lymphoedema.

The inclusion of lymphoedema compression garments on the drug tariff means that community nurses will have access to garments through the prescription process. This clearly has implications for the training of community nurses, particularly in the assessment and measurement of limbs, the prescribing process and establishing clarity about limits of competence. Complex cases with limb distortion will continue to require specialist assessment and management, including the prescribing of appropriate compression garments.

#### New research

There is a notable lack of research evidence to support

the care given to people with lymphoedema, which has been highlighted in a series of systematic reviews (Badger et al, 2004a,b,c). Several important qualitative studies have focused on the effects of lymphoedema on the individual but most of these concentrate on women with breast cancer-related lymphoedema (Tobin et al, 1993; Woods et al, 1995; Passik and McDonald, 1998). Studies that examine the experience of people with lymphoedema of causes other than breast cancer do exist but they are rare, a notable recent exception being a phenomenological study by Williams et al (2005).

The NLF provides a rich pool of patient and practitioner experiences from which much can be learned and which can effectively contribute to the care of this patient group in the community. A number of research studies have been initiated as part of the framework project, which aim to provide information for those caring for people with lymphoedema that is of real practical use and based in the real world of the community setting. These include two qualitative studies, one focusing on the experience of frail older people with lymphoedema, and the other on the experiences of children with lymphoedema and their families. A national study to determine the prevalence of lymphoedema in children will also be undertaken over the next two years. A major piece of work closely associated with the NLF is looking

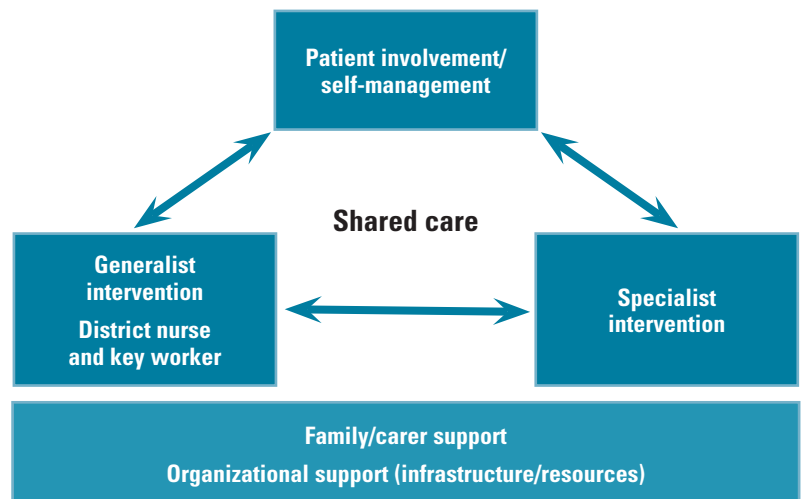


Figure 2. A model of shared care.

at the psychosocial issues of lymphoedema by comparing people with lymphoedema (cases) with the general population who do not have the condition (controls). In addition, preparations are in progress for a major study into the use of bandages, which will seek to understand the performance of interface pressures and the effectiveness of different bandaging regimens.

Table 1. The roles of community nurse and key worker in a primary care-based lymphoedema service

The community nurse	The key worker
<ul style="list-style-type: none"> <li>◆ Identify those at risk of developing lymphoedema</li> <li>◆ Recognize stage and severity of lymph edema and determine whether it is within their scope of practice</li> <li>◆ Refer appropriately to a specialist</li> <li>◆ Plan implement and evaluate skin care regimes</li> <li>◆ Recognise cellulitis and take appropriate action</li> <li>◆ Understand and support patients to manage long term preventive strategies for cellulitis</li> <li>◆ Plan, implement and evaluate long term care for a patient with mild lymphoedema with no distortion</li> <li>◆ Select appropriate bandaging techniques based on shape of limb, stage of lymphoedema and skin condition</li> <li>◆ Undertake simple spiral multi-layer bandaging</li> <li>◆ Undertake palliative bandaging for patients with advanced stages of cancer</li> <li>◆ Measure for, apply and monitor the effectiveness of ready to wear compression garments for patients with mild uncomplicated lymphoedema with no limb distortion</li> <li>◆ Train and support patients and their carers to apply and manage compression garments</li> </ul>	<ul style="list-style-type: none"> <li>◆ Manage community-based clinics</li> <li>◆ Provide support for other community staff in the care and management of patients with lymphoedema</li> <li>◆ Undertake lymphoedema assessments</li> <li>◆ Undertake modified intensive therapy (without MLD)</li> <li>◆ Manage the transition phase of treatment (under the supervision of the specialist)</li> <li>◆ Refer appropriately to the specialist</li> <li>◆ Measure for and fit custom-made compression garments</li> <li>◆ Initiate, apply and monitor simple multi-layer bandaging</li> <li>◆ Undertake more complex bandage techniques (under the supervision of a specialist)</li> <li>◆ Manage patients with lymphoedema who also have venous ulcers and who require full leg bandaging</li> <li>◆ Undertake full leg bandaging as part of an individualized plan of long term management</li> <li>◆ Manage patients with minimal (in terms of level of complexity) shape distortion</li> <li>◆ Manage the long term care of patients</li> <li>◆ Reassess the compression garment and bandaging needs of patients</li> <li>◆ Regularly reassess patients to determine whether referral to a specialist is required for intensive therapy</li> <li>◆ Provide and teach simple lymphatic drainage (SLD)</li> <li>◆ Assist in the training of community nurses and other health care professionals</li> <li>◆ Provide structured patient education</li> </ul>

## KEY POINTS

- ◆ The Lymphoedema Framework is concerned with the introduction of a model of integrated care and management in the primary care setting for people with lymphoedema of all causes.
- ◆ A model of shared care underpins this integrated approach in which the community nurse plays an important part.
- ◆ The role of the specialist lymphoedema practitioner is central to the success of this approach.

## The role of the community nurse

Service models introduced by participating PCTs as part of the NLF are, of necessity, complex and differ from each other in many respects. All, however, have at their centre the concept of shared care, within which the community nurse plays a critical part. The shared care approach is based on a strong working relationship between the patient (and their family and carers), the generalist practitioner (community nurse/link nurse) and the specialist lymphoedema practitioner. A model of shared care is given in *Figure 2*.

In practical terms this means the establishment of community lymphoedema clinics run by trained key workers (community nurses who have developed more specialist skills by undertaking appropriate training) and supervised by the specialist practitioner. Complex cases are managed by the specialist practitioner, with ongoing care and management being provided by the key worker together with the community nursing team as a whole and supervised by the specialist. To be effective it is important that the roles of community nurse and the key worker are clearly defined and an overview of both is given in *Table 1*.

In practical terms this means that the role of the lymphoedema specialist is expanded to include the management and supervision of the primary care-based integrated lymphoedema service. This expanded role is critical to the success of this approach. Service models will differ depending on the PCT context, but an example would be the establishment of community lymphoedema clinics managed and supervised by the lymphoedema specialist and run by trained key workers.

## Conclusion

This article has provided a brief overview of the National Lymphoedema Framework project and has highlighted the central role of the community nurse within it. This role – either as a key worker or as a member of the community nursing team with a caseload – will require education and training as well as commitment from the PCT to ensure an appropriate infrastructure and level of resource provision. The NLF is a vehicle for change that will hopefully provide the momentum for a gold standard in lymphoedema care that will be the envy of the world. What is clear is the critically important role of the community nurse in ensuring this exciting challenge is a success.

**BJCN**

**If you are interested in finding out more about the Lymphoedema Framework Project please contact:**  
**Dr Phil Morgan**  
**Centre for Research and Implementation of Clinical Practice**  
**Thames Valley University**  
**32-38 Uxbridge Road**  
**London W5 2BS**  
**Tel: (020) 8280 5070 or 5020**  
**Email: phil.morgan@tvu.ac.uk**

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