

# Improving the lives of patients with lymphoedema

Christine Moffatt, Professor of Nursing and Co-Director, CRICP, Thames Valley University

It is extraordinary that in today's health service there are still people suffering with chronic illnesses to which little or no attention is given. Unfortunately, this is the situation for many patients with lymphoedema, a condition that affects well over 100,000 patients in the UK.

Lymphoedema is a chronic progressive condition that is generally characterised by the swelling (oedema) of one or more limbs, and may include the corresponding section (quadrant) of the trunk. Swelling can also affect the head and neck, breast and the genitalia. It occurs as a result of an imbalance between lymph formation and lymph absorption.

There is a perception that lymphoedema is an uncommon problem in developed countries, and is mainly confined to people who have developed it following treatment for cancer. However, it has been reported that, at birth, approximately one in 6,000 people will develop primary lymphoedema and the overall prevalence of lymphoedema/chronic oedema has been estimated as 1.33/1,000 in the UK (Dale, 1985; Moffatt et al, 2003).

Until a few years ago, little attempt had been made to identify how many patients suffered with this condition. A lack of awareness and understanding among healthcare professionals of how to recognise and treat the condition meant that patients were often forced to go abroad to receive treatment or were told that nothing could be done for them.

While it is true that at present lymphoedema is not curable, it may be

greatly ameliorated with appropriate management. Many patients are unaware of treatments or where to

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obtain them and sadly, if ignored, the condition can gradually deteriorate and become difficult to manage. Lymphoedema can result in significant physical and psychological morbidity.

## **The Lymphoedema Framework Project**

The Lymphoedema Framework Project (LFP) was set up to try and tackle these issues and place lymphoedema care firmly on the healthcare agenda. This ongoing project involves collaboration between researchers, clinical experts from the British Lymphology Society, patients from the Lymphoedema Support Network (the patient support group for this condition), primary care trust representatives, other organisations such as Macmillan, and the wound care and compression hosiery industry.

Over the past few years, the LFP has been undertaking a number of initiatives to raise the profile of patients with lymphoedema, and to increase understanding of the condition among healthcare professionals.

## **Developing consensus on best practice**

Like many chronic conditions the research basis for lymphoedema care has been poorly developed. Three

systematic reviews undertaken by Caroline Badger (2004a;b;c) a pioneer in this field, highlighted a lack of traditional empirical evidence, in the form of randomised controlled trials (RCT) to support much of what is done in key areas of lymphoedema treatment and management.

This situation is not uncommon and sadly many systematic reviews come to a similar conclusion. However, a lack of research evidence does not mean that a treatment does not work.

Equally for a variety of reasons, not all aspects of care and management will have been the subject of research and, where this is the case, ways must be found to make use of other sources of evidence, such as professional and patient expert opinion (Ryecroft-Malone, 2001).

The project therefore had to take a different approach in reaching agreement about what care should be delivered in the absence of traditional research evidence. This was a mammoth task that involved developing working groups with representation from all those involved in lymphoedema care; both specialists and generalists. A rigorous methodology using clinical scenarios and cues, integrated with what was known from the literature were used to map the key elements of care. In addition to experts in the UK, an international panel were also established to critically appraise the work.

The first stage of the project involved the development of a set of agreed national standards that could be applied to all services delivering care to this patient group. Following this,

138 clinical recommendations were developed and appraised during the development of the document.

The resulting best practice document (available at [www.lf.cricp.org](http://www.lf.cricp.org)) aims to give clear advice on how patients with lymphoedema should be assessed and treated and when they should be referred for specialist care. As well as providing clinical advice it also makes recommendations on the level of training that practitioners require to undertake different levels of care. It is hoped that this document will be of use to all those involved in the care of patients with lymphoedema.

### Other initiatives

Other aspects of the LFP include developing services in primary care trusts throughout the UK. This initiative aims to show how effective care improves the clinical outcomes and psychosocial care for patients. One of the greatest challenges the project has faced so far has been the availability of the specialist

hosiery garments and products required for treatment through GP or nurse prescription. We are delighted that over the last year the Department of Health accepted our recommendations on a new classification for lymphoedema. This means that these products which are key to improving the lives of patients with lymphoedema are now readily available through primary care on the Drug Tariff. The previous system meant that hosiery was only available through hospitals, who were facing ever increasing pressures on their budgets.

Much work has to be done in preparing the way forward for prescribing in primary care, but this achievement is of major significance in terms of lymphoedema being recognised as an important issue.

Another aim of the LFP is to raise awareness and develop skilled practitioners through professional education and I am delighted that the first issue of the *Journal of*

*Lymphoedema* is being launched at the BLS in October of this year to help achieve this aim.

The *Journal of Lymphoedema*, working in partnership with the Lymphoedema Framework Project aims to help develop the clinical practice of all professionals involved in this area of care. The journal will be peer-reviewed throughout to ensure a consistent high editorial standard that reflects current clinical practice and issues surrounding lymphoedema care.

The editorial board will consist of leading figures in lymphoedema from around the world, all sharing a passion in the area and a drive to ensure the evolution of this exciting publication. Furthermore, the journal will seek to develop strong working relationships with all relevant organisations around the world, and is currently working with the British Lymphology Society and Lymphoedema Support Network.

The Lymphoedema Framework and its partners share a desire to reverse the desperate position which many patients with lymphoedema face currently. The combined initiatives described here are only part of a wider strategic approach to place lymphoedema care firmly on the health care agenda. **WUK**

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