

UNDERSTANDING THE IMPACT ON PATIENTS IS CRUCIAL FOR PRACTICE

Christine Moffatt

A major theme emerging through this issue of the journal is the impact of lymphoedema on patients, and the failure of healthcare professionals to truly acknowledge this in many aspects of everyday life. Geresa Dreyer portrays the horrifying experience of infestation with maggots (myiasis) and the humiliation and suffering this leads to. Few healthcare professionals working in western countries will appreciate the significance of this problem, drawing from their own experience of superficial infestation with maggots that only digest dead tissue rather than live tissue.

Anna Towers' research clearly indicates that issues such as pain and functional limitations are major problems to patients, which are denied by many healthcare professionals. This raises the importance of reassessing the focus of research and the recommendations that are made about treatment.

Sarah Spratt's account of living with lipoedema shows the plight of patients with this condition. This is such a neglected issue and the treatment options are as yet so limited. The picture of lack of diagnosis and treatment are a common phenomena seen in most countries of the world. Too many patients and families struggle to find knowledgeable professionals and face disappointments in their search for help.

Little attention has been given to the realities of being in employment if you are suffering from lymphoedema. Mei Fu's work shows that this is a significant issue and that slowly

research is emerging that highlights the personal and financial cost to patients. Researchers and clinicians must turn their attention to these issues and ensure that treatment methods are evaluated within the context of the impact on the patient's quality of life and psychosocial status.


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This journal aims to stimulate debate about many areas of practice. We are very pleased to see that this is occurring. There are probably few areas of lymphoedema practice in which opinions are so polarised than the use of liposuction. The last issue of the journal included a debate on liposuction from a conservative viewpoint. In this journal we see a well argued and balanced account of liposuction by Håkan Brorson who has pioneered this treatment. He shows that there is a growing body of evidence to support this treatment when administered correctly with long-term use of compression. This is just one area of practice that is being scientifically evaluated to determine its clinical- and cost-effectiveness. Many of the conservative treatments described as the 'gold standard' lack this scientific basis. Much research is required to identify the most effective treatment regimes for the diverse patient groups seen in clinical practice.

The rare case article discusses lymphoedema-distichiasis, and raises

awareness of the psychological affect that this syndrome can have on the patient.

The importance and involvement of patient support groups in the care of those suffering from lymphoedema should never be underestimated. Central to the ethos underpinning the *Journal of Lymphoedema* is the integral role of patients in ensuring that services meet their needs. The pioneering work of the National Lymphedema Network (NLN) is described in the society history section. There can be few patient organisations that have achieved as much as they have over the last two decades, and at huge personal cost. It is a sad reflection that in many countries of the world patients have to fight as hard as they do to obtain even a basic level of diagnosis and treatment. International collaborations such as the International Lymphoedema Framework (ILF) project and others are striving to change these issues and to value the patient as an expert in their condition and vital to the development of effective services.

The recently published, *Template for Management: developing a lymphoedema service* is an invaluable resource to those struggling to make the case for the development of lymphoedema services in different parts of the world and in different healthcare settings. The experience in the UK over the last few years has shown that many professionals lack the experience to tackle these issues. The tools within this document will assist in strengthening the development and sustainability of lymphoedema services. I urge readers of the *Journal of Lymphoedema* to obtain a copy from Medi UK by emailing: enquiries@mediuk.co.uk. 

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