

Specialist lymphoedema services: An evidence review

Introduction

Macmillan Cancer Support has invested a significant amount of funding in initiatives for people affected by lymphoedema, benefiting both cancer and some non-cancer related lymphoedema patients. Initiatives funded include health professional posts, grants for learning and development, self help support grants and cancer network grants.

Key findings

Lymphoedema is a chronic, incurable and debilitating condition which can have a serious impact on quality of life for patients. If not treated effectively, consequences can include long term disability, reduced quality of life, emotional problems and problems at work.

The prevalence and incidence of lymphoedema is difficult to determine as it is often misdiagnosed or confused with other conditions. However, estimates for the prevalence of lymphoedema in the UK range between 80,000 and 124,000 people.

The presence of lymphoedema in people with cancer can lead to significant distress for patients and their families. It presents challenges for health professionals and many do not feel that they have knowledge and skills to manage lymphoedema effectively.

Specialist lymphoedema practitioners are nurses, physiotherapists, occupational therapists or Manual Lymph Drainage therapists. They provide care for patients, give advice to both patients and professionals and obtain and disseminate lymphoedema information. Where specialist lymphoedema services are available patients experience an improved quality of life.

The removal of specialist lymphoedema services means that the workload of providing care to at least 80,000 people across the UK will fall on the wider healthcare workforce.

1. Why are specialist lymphoedema services needed?

i) What is lymphoedema?

Lymphoedema is the result of accumulation of fluid and other elements (e.g. protein) in the tissue spaces. It arises from congenital malformation of the lymphatic system (primary lymphoedema), or damage to lymphatic vessels and/or lymph nodes (secondary lymphoedema).

Lymphoedema is a long term condition that can be both distressing and debilitating¹. It is characterised by the persistent swelling of one or more limbs. Swelling may also affect other areas, including the trunk, head and neck, breast or genitalia².

One of the main reasons for referral for lymphoedema is association with cancer or its treatment. It is most commonly seen in people with breast or gynaecological cancers^{3 4} but can also result from the treatment of head and neck and prostate cancers, as well as sarcomas and melanoma⁵.

ii) How common is lymphoedema?

The prevalence and incidence of lymphoedema is difficult to determine as it is a relatively newly-recognised condition, has no agreed international definition and is often misdiagnosed or confused with other conditions.. For example, lymphoedema can occur as a consequence of cellulitis, or lead to recurrent episodes of cellulitis.⁶ The NHS Institute for Innovation and Improvement found that there were 45,522 inpatient admissions for cellulitis in 2003–2004.

A 2003 study⁷ conducted across the South West London Community Trust revealed a lymphoedema prevalence rate of 1.33/1,000 for all ages[†]. Other studies have shown similar rates, up to around 2/1,000.² This equates to between 80,000 and 124,000 people across the UK with the condition.⁸ To put this in to context, this is similar to UK prevalence rates for Parkinson's disease⁹, multiple sclerosis¹⁰ and HIV.¹¹

These prevalence figures are likely to be an underestimate due to lack of national data and poor identification of the condition.

Prevalence rates of 12-60% have been reported in breast cancer patients^{12,13,14} and of 28-47% in patients treated for gynaecological cancer.^{15,16} There are, however, significant numbers of patients for whom cancer is not the cause of lymphoedema. The 2003 study⁷ referred to above found that only 25% of lymphoedema cases were due to cancer therapy.

iii) Why are specialist lymphoedema services needed for people living with cancer?

Lymphoedema is not a curable condition but can be alleviated with appropriate management. A study of over 700 chronic odema/lymphoedema patients in Scotland found that 97.5% of those who received specialist care had their swelling controlled, compared to fewer than 80% of those treated by non-specialist services.¹⁷

Lymphoedema specialists provide support and give advice to both patients and professionals, obtain and disseminate lymphoedema information and provide lymphoedema patients with a standard of care which is recognised by the British Lymphology Society, working alongside the recommendations of the International Lymphoedema Framework Project.¹⁸ Specialist lymphoedema practitioners are predominantly nurses, physiotherapists and occupational therapists¹⁹ and can also include Manual Lymph Drainage (MLD) therapists.[‡]

"I just feel supported in a way I didn't before, I felt very isolated before and a bit frightened really about what was going on in my body, you know what might go on as years pass? Whereas now I know I can come here and speak about it openly and you know they'll tell me, you know they'll give me option and let me work out what I want to doit's when I came here to the clinic and I think the first time that I felt properly supported, that I really fully accepted it and felt accepted it to the extent that I could speak about it to other people"¹⁷

† The study also found that prevalence increases with age, with rates of around 5.4/1000 in the over 65's and 10.3/1000 in the over 85's.

‡ Manual Lymph Drainage (MLD) is the specialist massage technique used in treatment of Lymphoedema

2. What are the potential consequences of withdrawing specialist lymphoedema services?

i) The consequences for cancer patients

Many patients across the UK already have problems accessing lymphoedema treatment.²⁰ The withdrawal of existing services would exacerbate this problem. If allowed to progress untreated lymphoedema can become very difficult to manage^{21 22} and can lead to long term disability, difficulties with work, emotional problems²³ and reduced quality of life^{24 25}:

"I was really ill with infections (15 times a year) and the doctors couldn't understand what was wrong with me...it was a locum who came and sent me to the lymphoedema clinic"¹⁷

Specialist services allow patients to be diagnosed and treated more quickly than may otherwise have been the case, and ensure access to a 'whole package of care' rather than having to be referred on.²⁶ Where specialist lymphoedema services are available patients experience improved quality of life²⁷:

"I had surgery to remove a tumour in my stomach and was told that I might get some swelling in the arm, which would be a normal side effect to the radiotherapy treatment and the surgery. No further information was given on how to deal with it. The lymphoedema practitioner changed my life with MLD [manual lymphatic drainage] and CDT [compressive decongestive therapy]"

Specialist roles provide care for patients with chronic and persistent conditions which generalists may not have the skills to deal with effectively. Community nurses, for example, consistently report they don't have knowledge and skills to manage lymphoedema.²⁸

Withdrawing specialist services means that the international standards for the management of lymphoedema may not be met. The guidance states that 'all people at risk of, or with, lymphoedema will have access to trained healthcare professionals, including lymphoedema specialists'.²⁹

Case Study – Highly Specialist Lymphoedema Service (HSLs) North Yorkshire

Breast cancer patients from this service reported the following risks of withdrawing the service:

- Increased risk of infections (cellulitis)
- Unable to find clothes to fit, particularly sleeves wide enough for a swollen arm
- Fear of cancer recurrence

A breast cancer patient being treated at HSLs had received Complex Decongestive Therapy (CDT) once a year before access to the service. She suffered repeated cellullitic attacks and had to be hospitalised on one occasion for intra-venous antibiotics.

Once referred to the HSLs service she also received regular 4-6 weekly CDT top ups. She reported that these top ups significantly reduced the number of cellullitic attacks, kept her lymphoedema more under control and helped prevent the recurrence of cellulitis.

i) The consequences for other healthcare professionals

Withdrawal of specialist services will place a heavy burden on inexperienced practitioners^{30,31} and on physiotherapists in particular.³²

"I try to fit them in around my other working commitments. If however we are carrying a vacancy or if we've got people off sick or anything like that, then my chronic oedema time drops..."¹⁷

ii) The consequences for local health and social care economies

Advanced and Specialist Nurses make a difference to patients' lives and have a beneficial impact on the health service they work in.³³ Lack of specialist lymphoedema service provision may mean that patients are receiving less effective care at higher cost.³⁴

The NHS Institute for Innovation and Improvement noted that there were 45,522 inpatient admissions for cellulitis in 2003–2004, costing the NHS £87m.³⁵ As specialist lymphoedema services help reduce the occurrence of cellulosic attacks, the removal of these services could cause expenditure to rise.

The Royal College of Nursing (RCN) says that reducing spending on specialist nurses is a false economy, because these nurse posts save money from health budgets. It gives examples of annual savings that can be delivered by specialist nurses³⁶:

- £56 million on care for people with Parkinson's disease
- £180 million by treating multiple sclerosis flare-ups at home rather than in hospital
- £84 million by using nurse specialists— rather than GPs – to manage epilepsy

3. How does Macmillan help to meet the need for specialist lymphoedema services for cancer patients?

Between 2006-2009 Macmillan invested around £1.7m in initiatives for both cancer and non-cancer related lymphoedema patients across the UK. Funding streams include professional posts, learning and development grants, self help support grants and cancer network grants. Professional posts are a mix of Occupational Therapists, Physiotherapists and Specialist Nurses.

In order to provide the best possible quality of life for patients and their families, the management of lymphoedema in people with advanced cancer requires a well coordinated, multi professional team approach. This should include initial assessment and specialist advice from practitioners who have completed specialist lymphoedema training where available.^{37 38}

In 2006, the Lymphoedema Framework produced a document called the Best Practice Guidelines for the Management of Lymphoedema: International Consensus.¹ These guidelines support development of Macmillan's services.

The Macmillan Lymphoedema Academy Community of Practice (MLA CoP) offers training in specialist lymphoedema management and regularly updates teaching materials in response to research and development in the treatment of lymphoedema. Since 2004, the MLA has trained over 500 practitioners across the UK. These in turn have passed skills on to other professionals as well as treating many patients and teaching them to manage their own condition.³⁹

Case Study - Abertawe Bro Morgannwg University Health Board Lymphoedema Service Led by Macmillan Lymphoedema Physiotherapy Specialist Melanie Lewis

Set up in 2001 this pioneering and award-winning service has helped more than 2,000 patients in the last ten years. When the service began only cancer patients were able to access help, but in 2005 patients with other medical conditions began to be treated as well.

Using techniques including massage, compression bandages, skin treatment and controlled breathing, the service both treats patients, and also helps train patients and their carers to apply the treatments at home.

For every £1 spent on lymphoedema treatments the service estimates that, by limiting swelling and preventing damage and infection, the NHS saves £100 in reduced hospital admissions.

"The self-management approach has helped many women recover and led to a reduction in the risk of lymphoedema from 25 per cent to 12 per cent in breast cancer patients." - Ann Green, chair of the Chartered Society of Physiotherapy on presentation of an award to the service

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