

# Navigating the Health Care System

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## Background

The provision of care for lymphoedema patients varies from area to area, depending on funding and available resources in terms of access to specialist services on the NHS (Morgan P, 2005, Todd 2006). This poster will discuss the experiences of patients who had had problems accessing treatment for lymphoedema. The main case study focuses on a young patient who presented to the specialist service with primary lymphoedema having had inappropriate treatment resulting in a lack of confidence. The awareness of lymphoedema is becoming more well recognised with practitioners learning new skills to complement the knowledge and treatment regimes that are already in place (Lymphoedema Framework)

## Objectives

To outline the problems the client encounters during the process of accessing healthcare for lymphoedema treatment.

Present clients' statements of experiences.

Discussion of practitioner's constraints – the difficulty in convincing healthcare providers of appropriate dressings and compression.

Highlighting legal, moral and cost issues.

## Clients' experiences

**Mr K:** "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)"

**Ms Z:** "My doctor did not listen to me when I told him that I had pain in my legs. He suggested that I go on a diet and lose some weight. The specialist practitioner referred me to the local hospital for checks for suspected lipodema, and MLD and CDT were commenced, but this was not available on the NHS"

**Mrs L:** "Following a bilateral mastectomy, my arms became heavier and heavier, but there was no longer funding for the service and I was told to try a private practitioner. The treatment is fantastic but I am struggling to fund it. It really should be on the NHS to all sufferers"

## Mrs N's Story

Mrs N is a 44 year lady with a long standing history of primary lymphoedema. When she first presented to the lymphoedema specialist's clinic her right leg showed the result of debulking surgery as a quick fix. The surgery had led to the destruction of the lymphatics with disfigurement and visible scars from a skin graft attempt (pic). An attempt at compression by a previous centre had been unsuccessful and resulted in cellulitis, after which Mrs N refused to continue with the bandaging, opting instead for compression tights over foam padding. No MLD or SLD (simple lymphatic drainage) had been given.

## The treatment

The specialist had to win her confidence and implement treatment that would be appropriate and effective.

MLD was commenced with good effect and the patient was shown how to perform SLD, continuing with her hosiery to build up her trust. The shape and volume on the right lower leg and foot improved and the distal volume reduced by 350 mls. But fluid had gathered above the knee by 325mls., clearly indicating the need for higher compression on the thigh.

Vascular tests at the hospital confirmed that it was safe to apply high compression bandages, and it was decided to use a cohesive short stretch bandage (Actico®) to bandage the leg from toe to thigh without slippage. Full leg bandaging is now being used more widely with this system (Williams A, 2006). Wool padding was applied and held in place by a tubular retention bandage to shape the leg in preparation for

compression bandaging. However, because of the shape of her leg, the padding did not stay in place, so foam padding was used over the wool padding which was still used to fill in the gaps and skin folds (Williams A, 2006).

## Results

In less than 3 weeks she had lost 2.5 litres, and her husband was taught to bandage her leg. With training and supervision he has become competent reducing bandaging time from 2 hours down to 30 minutes. Treatment is on-going weekly, and at times twice a week with MLD and bandaging.

## Discussion

In many parts of Britain, the service for lymphoedema sufferers is not available on the NHS and when these sufferers are fortunate enough to find a lymphoedema practitioner in their area, the lymphoedema practitioner is most likely faced with the difficulty in convincing the healthcare providers of appropriate dressings, compression garments/bandaging. The expense of treatment, understanding of how manual lymphatic drainage works, and the knowledge of new compression therapy all need to be considered when deciding on treatment.

## Conclusion

The patient's charter states that all patients have a right to receive health care on the basis of clinical need, not on the ability to pay, regardless of lifestyle or any other factor, so why does this not apply to lymphoedema? With the right knowledge, training and availability of treatment, patients who previously had received inappropriate or no care are now beginning to have access to treatments that will change their lives.

## References

Morgan P, Moody M, Franks P, Moffatt C, Doherty D (2005) assessing community nurses' level of knowledge of lymphoedema. BJN 14 1 : 8-13

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