

Abstract of the Presentation for Gent Symposium (26 May 2018)

The Patient Journey In the UK – Denise Hardy (Lymphoedema Nurse Consultant)

Lymphoedema is a long term, chronic condition and its recognition/management in the UK has taken over 30 years to come to fruition. Sadly it remains a 'post code lottery' with services varying considerably up and down the country. Majority of clinics are nurse/physio led and very few have medical input. However most do tend to have a holistic approach to manage this often-debilitating condition, putting the patient in the forefront of care planning and treatment.

This presentation will focus on one such clinic in the North West of England – Kendal Lymphology Centre (KLC) – an independent clinic with NHS funding. It will highlight the different types of patients' seen/referred (including adults/children with primary/secondary lymphoedema, chronic oedema and lipoedema) and will discuss the care pathway and components of care used to enable such patients to self-manage this long term, chronic condition. Denise Hardy will share with the audience, the education programme KLC has in place to enable the patient to become an 'expert patient' and will highlight the importance of shared care and a multi-disciplinary team approach.

QUESTIONS:

1. **Assessment of the 'swelling' is crucial to successful management.**
Is this statement **True/False?**

Holistic assessment is vital to understand the underlying cause of the swelling, which may have many different exacerbating features. KLC explores all avenues (without medical input) to ascertain the underlying cause of the swelling, instigating an appropriate, realistic care plan pertinent to the individual patient

2. **'It is crucial that patients are referred as early as possible to a lymphoedema clinic in order to achieve successful management'**
Is this statement **True/False?**

In an ideal world patients would be seen BEFORE swelling became evident. Patients at particular risk – e.g. patients treated for cancer, obese patients, those with recurrent Cellulitis) – or at least be referred as soon as swelling became evident (after ruling out acute causes). However, funding limitations generally preclude that and KLC often has to treat patients who have had lymphoedema/lipoedema for many years without any intervention whatsoever.

3. **'As Lymphoedema is a life-long, chronic condition, patients will never be discharged'**
Is this statement **True/False?**

KLC aims for all patients to be discharged within 18-24 months from referral - as an expert patient who is able to self manage their own condition (through patient education with high quality (appropriate, personal, relevant) information about their condition with on-going emotional and peer support (through support groups) . Once stable garments are put on repeat prescription. An advisory clinic is available for discharged patients who have problems after discharge – or who need a re-measure for new garments.

4. Obesity is a risk factor for the development/regression of lymphoedema and makes successful management difficult. Should patients be encouraged to lose weight BEFORE being seen in a lymphoedema clinic?

Yes/**No**?

Preliminary findings from the ILF LIMPRINT report found 34% of lymphoedema cases were also obese. Many patients have lost all hope of improving their swelling and therefore have no incentive to lose weight (exacerbating the lymphoedema as a result). Treating the patient holistically (including weight management) will enable the patient to re-gain control – especially as they see on-going improvement in the lymphoedema.

However, patients must WANT to make a difference to their own lives – they have to demonstrate they are trying to lose weight/exercise and if not, they are discharged from the service with appropriate self-help advice they feel they CAN implement (skin care, elevation, gentle remedial exercises etc)

5. Lipoedema is an increasing problem in the UK and many women are told they are just overweight. What advice is the best for such patients:

- a) Weight management (healthy eating), hydrotherapy, compression garments
- b) Manual Lymphatic Drainage (MLD), Multi-Layer Bandaging (MLB), non-weight bearing exercise
- c) Liposuction
- d) All of the above**

Patients with lipoedema vary considerably – some will benefit from MLD (if painful); some will not. Others may have orthostatic oedema that would respond to MLB; others will be better using compression garments. All patients would benefit from water therapy and weight management. Liposuction maybe an option when conservative treatment has been implemented and unsuccessful.