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A CASE FOR SPECIALIST PRACTICE

Jane Wigg

The International Society of Lymphology (ISL) consensus document (2003) and the Lymphoedema Framework (LF) consensus document (2006) provide guidelines to support Best Practice for lymphoedema management. In extreme cases, such guidelines may require creativity and modification to suit patients' needs. This case report shows the treatment and support needed to assist a patient with gross lymphoedema. The combined treatment approach with multilayer lymphoedema bandaging, LymphAssist therapy and specialist garments proved successful with limb volume reduction and increasing the patient's mobility and confidence.

Key words

Specialist practice
Primary lymphoedema
Combined treatment
Compliance

It is internationally recognised and well documented that a combined approach to lymphoedema management, utilising manual lymphatic drainage (MLD) and multilayer bandaging achieves the best possible outcome for patients (International Society of Lymphology [ISL], 2003). The importance of such an approach, together with the compliance and commitment required from the patient, is demonstrated in the following case report of a patient with gross lymphoedema.

Case report

Sarah (pseudonym to protect identity), a 43-year-old married lady with three young children developed unilateral oedema to the left leg during her third pregnancy at 20 weeks' duration.

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Following a caesarean section in 1999, the oedema increased significantly, mainly in the calf where the tissues became thickened and there was minimal oedema in the foot when she presented at the author's clinic in 2007. Her only other past medical history included surgery for a complicated umbilical hernia repair involving the

Accurate diagnosis is essential to allow the patient to adjust to the condition and accept its challenges of care.

bowel in 2004 and medication of frusomide 40mg daily, which had been prescribed by her GP six weeks before her first assessment in clinic as a method of controlling the oedema. At her initial assessment it was suggested that this be discontinued. Sarah was morbidly obese with a body weight of over 200kg. She was unable to be weighed at her first appointment, due to her weight exceeding clinic scales.

The increase of Sarah's oedema and body weight over a six-year period now limited her mobility, necessitating her walking with two sticks. Due to her weight gain and lack of treatment for oedema, Sarah had become increasingly depressed and disillusioned about her future and the National Health System.

Assessment

Sarah presented at the specialist lymphoedema clinic with a gross lymphoedema of the left leg in the summer of 2007.

Following her first assessment which included a full holistic assessment, a diagnosis of stage III primary lymphoedema with elephantiasis, exacerbated by obesity was confirmed (ISL, 2003). Billingham (2008) has highlighted the importance of an holistic assessment to achieve accurate diagnosis, which includes the physical, social, psychological and spiritual aspects of patient care. Accurate diagnosis is essential to allow the patient to adjust to the condition and accept its challenges of care. Honnor (2008) stated that the success of long-term management of lymphoedema was achieved by providing patients with appropriate education and knowledge of their condition, 'enabling them to gain control'. Once diagnosed, Sarah could relate to the causes of the oedema and, through a better understanding of her condition, was empowered to make the health-related decisions necessary to improve it.

Obesity has a direct bearing on the development of chronic oedema and predisposes the individual to episodes of cellulitis (Lewis and Morgan, 2008). Cellulitis is a common problem in gross lymphoedema and recurrent episodes not only damage the



Figure 1. Limb condition on day one of treatment.

lymphatic system further, but increase healthcare costs due to hospital admissions (Keeley, 2008). Sarah had suffered several bouts of cellulitis for which, although not requiring hospital admission, she had needed antibiotics and bed rest. This impacted on her quality of life by inhibiting her activities of daily living and her role as mother to the family. In addition, Sarah had several open puncture wounds to the skin which needed appropriate dressings and also increased the risk of cellulitis.

Outcome measures for lymphoedema management generally focus on the visual effects of treatment, using limb volume reduction

and changes to skin and subcutaneous tissues. However, non-measurable effects such as improved morale and confidence often have more impact on the patient's quality of life (Woods, 1995; Sitzia and Badger, 1997). Outcome measures were agreed upon by Sarah and the therapists involved in her care, including limb volume reduction and increased mobility, followed by weight loss and an improvement in self-esteem. Sarah had encountered a great deal of negativity towards her obesity which had reduced her confidence. The knowledge that she was to be treated by a team of enthusiastic therapists gave her the confidence to hope for change in her condition.

At the initial assessment a plan of care was agreed in accordance with Best Practice guidelines (Lymphoedema Framework, 2006). However, complex cases require specialist intervention with therapists who have the experience, knowledge and confidence to adjust standard practice. Sarah's treatment involved multilayer lymphoedema bandaging, weight loss, manual lymphatic drainage (MLD) or intermittent pneumatic compression (IPC) (LymphAssist), skin care and exercise. However, this treatment needed to be adjusted to accommodate the advanced stage of her lymphoedema. Due to the severity of the limb, phase I treatment could not be combined with MLD or IPC (Professor Földi described the treatment of complex physical therapy [CPT] as phase I of decongestion and the ongoing maintenance in the following years as phase II of optimisation and conservation). To successfully manage gross lymphoedema, not only the patient's health has to be considered, but also that of the therapist. Risk assessments have to take place in accordance with clinical governance, moving and handling guidelines and Health and Safety at Work acts to ensure that the therapist is not at risk of injury through handling heavy limbs (Department of Health [DoH], 1974; Health and Safety Executive [HSE], 2004). Lymphoedema management is

a physical job and protection of the therapist over a long career needs to be paramount. In this case, a risk assessment was carried out and the provision of two lymphoedema therapists were allocated to Sarah's care. A healthcare assistant or physiotherapy helper is appropriate to work alongside the lymphoedema specialist. Although this inevitably increases the cost of care, it reduces the overall risk to both the patient and therapist and provides improved treatment and care.

Outcome measures

To assess treatment outcomes, baseline measurements of limb volume, photography, quality of life and mobility assessments should be taken (Keeley, 2008). Limb volume measurements within Sarah's lymphoedema service are taken using a perometer® (Juzo). In this instance, although available, a volumeter could not be used as Sarah was unable to support her leg in the appropriate position to undertake the measurement, and the diameter of the limb was too large for the perometer's field. Tape measurements offer an alternative method of obtaining circumferential limb volume measurement for evaluation purposes, together with photographic evidence to detail visual size, shape and skin condition. Consent must be gained before taking photographs for medical evaluation and teaching purposes, and, in this case, publication. Due to the severity of the limb size, it was decided that measurements taken at the ankle, calf and thigh would be appropriate for assessment of Sarah's care. Measurement is important but it is not the only outcome of treatment. Sometimes patients can become dependent upon their measurements, which can have a negative impact especially for palliative patients where goals are not always volume reduction.

Treatment

Multilayer lymphoedema bandaging was planned daily for the first two weeks, with the aim of reducing the limb volume with minimal effort and risk to the therapist and

allowing Sarah to adjust to strong compression bandaging. In addition, her limb was too large to fit into a intermittent pneumatic compression sleeve and MLD appointment times at this point would use excessive resources when balancing care in a hospice service. The third week would involve bandaging three times a week when she would be measured for compression garments. Continuing treatment within Wolverhampton lymphoedema service (WLS) consists of IPC or MLD weekly for two weeks, fortnightly for two weeks, reducing it to monthly thereafter focusing on maintenance of results and prevention of refill of oedema. It is essential at the outset of treatment to consider long-term management and how the patient will self-manage after the intensive treatment stage.

Modified treatment plan due to severe lymphoedema

- ▶ Daily bandaging (Monday–Friday) for three weeks
- ▶ Bandaging three times a week for two weeks
- ▶ Fitting with compression hosiery when appropriate
- ▶ Skin care with emollient
- ▶ Exercise
- ▶ LymphAssist when appropriate

Day 1: skin care was carried out using an emollient to the affected limb (Figure 1). In severe skin changes daily application of a urea-based cream is useful to rehydrate the tissues. Modified lymphoedema bandaging was applied with minimal sub-bandage pressure due to the increased risk of cellulitis, compliance issues with multilayer bandaging, and application due to the distortion of the limb. The foot had minimal oedema but necessitated being bandaged as a 'stump' separately to the leg because of the shape of the calf. Clinistretch Shortco (Haddenham Healthcare) was used for this purpose to ensure that the bandage did not slip off the foot and could anchor better at the heel. Due to the shape distortion and size difference from the heel to the calf it was likely that bandages would move. Clinistretch Shortco has the same

properties as a cotton short-stretch bandage, but due to its cohesive nature can stay in place longer and prevent slippage (Lymphoedema Framework, 2006). Often, a cohesive layer is applied over standard short-stretch bandages within clinical practice at WLS (Lymphoedema Framework, 2006).

Day 2: increased pressure was applied to the bandaging system over a two-day period to assist the patient to accommodate to bandaging. This was further increased to use very high pressure short-stretch and cohesive combined bandaging. Considering Laplace's law, which states that 'pressure is greatest over the smallest circumference', many layers of bandaging were required to ensure appropriate pressure was applied over the 101 cm calf measurement which had thickened tissues (Lymphoedema Framework, 2006).

After six treatments the limb had increased mobility and function and Sarah could maintain the limb in elevation during the bandaging session while seated in a chair. Skin thickening was reducing and Sarah reported that she was feeling the benefit of the treatment (Figure 2).

By day 12 (third week), Sarah reported a 'massive improvement' in her mobility. The calf showed a reduction of 10% (11 cm), and Sarah's skin condition had improved further (Figure 3).

Ongoing care

Due to risk assessment and the resource issues already mentioned, Sarah had previously been excluded from IPC or MLD treatment using WLS protocols. With a calf measurement of 89cm the calf now partly fitted the 'Flowtron Hydroven™ 12' wide-leg garment with insert. A modified course of IPC was prescribed as the foot and calf only fitted the thigh section of the garment.

The Flowtron Hydroven 12 which is manufactured by Arjohuntleigh and distributed by Haddenham



Figure 2. Limb reduction and shape improvement after only five treatments.



Figure 3. Limb on completion of phase I treatment when custom-made garments were fitted to accommodate shape. Note improvement of skin.

Haddenam



Figure 4. Following six months of treatment with LymphAssist and double layer class 2 garments.

Healthcare has a uniquely designed, LymphAssist cycle. This has been specifically designed to mimic MLD and will not exert pressures above 40mmHg. The cycle starts proximally and moves distally providing five inflations in each of the twelve chambers, assisting lymphatic and venous drainage. Using LymphAssist to provide MLD mechanically

reduces the risk to therapists when handling heavy, oedematous limbs and offers a means of self-management under supervision. Three cycles of 'LymphAssist' were carried out with the cycle being stopped each time it reached Sarah's foot (the garment was hanging over the foot). The LymphAssist cycle is programmed to always complete a full cycle and would therefore continue inflating the garment while it was hanging off her foot which would have no effect. Once the limb reduced further in size and the LymphAssist sleeve fitted the leg correctly, stopping mid-cycle was not required.

Boris et al (1998) have linked IPC to inducing genital oedema, but this was utilising high pressures over long periods of time. Recent studies using the LymphAssist mode have not found this and have recorded a noticeable change in tissue softening (Wigg, 2008).

On completion of day 15, there was a significant improvement in skin condition and an overall reduction of 14cm to the calf. The tissues were now soft and mobile with irregular thickening and the small, superficial puncture wounds present at the beginning of treatment had started to heal (Figure 3).

After only 17 treatment sessions, a class 4 made-to-measure Goldpunkt Dur hosiery provided by Haddenham Healthcare was fitted. It is normal practice within WLS to fit very strong garments after a course of decongestive lymphatic therapy (DLT), as this reduces the likelihood of needing to carry out a second course of DLT, which can utilise extensive clinic recourses. The use of a firm, rigid, flat-knit garment such as Goldpunkt Dur or Elvarex 4 super (BSN-Jobst) can prevent refill of the tissues and is generally easier for the patient to tolerate than a circular-knit garment.

Refill of the tissues occurred after five days, while waiting for delivery of a second layer of class 4

hosiery. Double layering is also used as standard practice within WLS, and is introduced immediately refill is detected to the tissues following DLT. A limb of such severity would be expected to refill and therefore Sarah would automatically have been prescribed two layers of garments at the outset. Sarah was taught how to independently self-bandage using a cohesive short-stretch bandage to maintain the oedema to the calf, while waiting for delivery of the second layer of garment. Sarah continued with LymphAssist therapy in clinic 2-3 times weekly until a loan pump was provided on 14th November, 2007 for long-term management at home. She was prescribed three cycles daily at 40mmHg. By this time Sarah, who had received treatment at clinic for only five weeks, was now self-caring.

On completion of phase I, the treatment plan was re-evaluated. Treatment goals had been partly achieved but Sarah was keen to lose more weight. Coping psychologically with the daily treatments had inevitably been having an effect on her home life. However, Sarah was now able to concentrate on weight loss, as well as her self-care management programme of skin care, daily LymphAssist therapy, wearing a double layer of class 4 compression hosiery (one layer at night) and self-lymphatic drainage for the dependent abdominal oedema. Supported by the hospital dietetics department and self-funded, Sarah began the 'Cambridge diet' in February 2008.

Sarah was reviewed at three-monthly intervals and was achieving a weight loss of 6kgs per month. After six months of treatment, Sarah was mobilising without sticks, wearing normal footwear and make up. Her confidence had grown and her weight reduced. She increased her physical activity and used an elliptical trainer. By June 2008 the limb had continued to reduce further (Figure 4) with the shape of the limb normalising leaving the skin loose. Clinical experience at WLS in treating severe cases such as Sarah's has not warranted that patients



Figure 5. Limb following 14 months of treatment (one year using only LymphAssist and garments).

undergo surgical refashioning of the skin. Given time, the skin reforms and accommodates the new limb shape. On this occasion, surgery was discussed with Sarah for abdominal reshaping and liposuction to the leg. However, in view of the psychosocial aspects of these procedures, it was agreed to wait a further three months and continue with the present treatment regime. The LymphAssist garment now fitted the limb normally and was continued for three cycles daily at 40mmHg.

In December 2008 the limb had returned to a normal shape and the tissues were soft and supple (Figure 5). Perometry measurements taken showed an excess volume of 33% (2722mls). A weight loss of 11 stone had been achieved with the Cambridge diet, exercise and limb volume reduction. Sessions of LymphAssist were reduced and a Farrow Wrap was introduced for long-term care. Due to the extensive reduction of oedema, the tissues, although hydrated, can refill while the elasticity of the skin returns. In the author's opinion, FarrowWrap provides the limb with similar properties to short-stretch bandaging through its rigid approach. In this

case, with the reduction of daily LymphAssist, it was important to prevent refill. FarrowWrap was an acceptable alternative to the second layer of hosiery and was easy to apply.

Sarah had been referred to the local plastics department regarding the dependent abdominal apron left from oedema and obesity, but local policy for abdominalplasty and reshaping includes the need for a maintained body weight of two years and a BMI of <27. Due to the extensive abdominal oedema, Sarah had a higher BMI than 27 which had not been maintained for two years. She was therefore refused surgery (Figure 6b). The abdomen alone has a minimum weight of 8 kilos. While waiting for an appeal to reconsider surgery and local policy, the abdominal oedema has been supported with a purpose-made 'ETO' abdominal support garment from Haddenham Healthcare. Dependent abdominal oedema can benefit from MLD, however, risk factors need to be considered if MLD treatment is to be used. At review in February 2009, Sarah had an excess volume of 31% (2500mls) and a calf measurement of 53cm (overall reduction of 48cm), the limb had maintained and the tissues were normalising (Figures 6a).



Figure 6a. After 16 months of treatment, massive improvement can be seen in the shape of the limb and skin condition; Figure 6b. Abdominal apron to be treated with 'ETO' garment and surgery; Figure 6c. cellulitis to abdominal apron.

Throughout the treatment process Sarah has not suffered from another episode of cellulitis to the limb. This demonstrates the need for limb volume reduction to reduce the protein content from the limb. In February 2009 Sarah required a course of antibiotics due to cellulitis of the abdomen (Figure 6c). Following the British Lymphology Society (BLS) and Lymphoedema Support Network (LSN) guidelines on cellulitis, prophylactic antibiotics have now been commenced to prevent deterioration to the limb (BLS and LSN, 2007).

Conclusion

This case report has demonstrated that through a combined treatment approach for gross lymphoedema, remarkable results can be obtained. The use of specialist lymphoedema bandaging and innovative LymphAssist treatment sessions, combined with creative and aggressive compression treatments for both limb and trunkal oedema, show that specialist lymphoedema practice and maintenance of specialist lymphoedema skills are essential in the management of complex lymphoedema.

In addition, consideration of the psychosocial aspects of care and approaching treatment issues in a timely nature when the patient feels adequately equipped to deal confidently with them improves outcomes. Specialist units provide an appropriate setting to carry out complex lymphoedema care by having access to specialist equipment and appropriately skilled staff. However, consistently heavy workloads can be detrimental and the therapists' well-being should be considered in the development of service design.

Sarah's treatment is not over, she still has to continue weight loss and stay motivated while waiting for abdominal surgery and to wear the strong garments. However, she is a changed person and will be renewing her wedding vows in the summer and has booked to take

her family on holiday to Florida. For Sarah, this is the greatest result from treatment because, as she says, she 'is now able to restart her life'. For the lymphoedema specialist, a case like Sarah's is certainly rewarding to treat, but life-long commitment from the patient themselves is paramount for its continuing success. JL

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Key points

- ▶▶ The timely manner of approaching goals is essential to outcomes.
- ▶▶ Outcomes for lymphoedema management are generally focused on the visual effects and limb volume reduction, when often non-measurable effects can have much more impact on the patient's quality of life.
- ▶▶ The Flowtron Hydroven 12, LymphAssist cycle has been uniquely designed to mimic MLD and cannot exert pressures above 40mmHg.
- ▶▶ FarrowWrap provides the limb with similar properties to short-stretch bandaging through its rigid approach.
- ▶▶ Specialist practice and maintenance of specialist skills are essential in the management of complex lymphoedema.
- ▶▶ For the lymphoedema specialist, a case like Sarah's is certainly rewarding to treat but life-long commitment from the patient themselves is paramount for continuing success.