Bedfordshire and Hertfordshire INTERIM Priorities Forum statement
Number: 5
Subject: Lymphoedema
Date of decision: September 2014
Date of review: September 2015

INTERIM Guidance

Lymphoedema is the result of accumulation of fluid and other elements (e.g. protein) in the tissue spaces due to an imbalance between interstitial fluid production and transport (usually low output failure) (International Society of Lymphology, 2003).

Summary

- The priorities forum recommends funding the management of lymphoedema for all types of chronic lymphoedema present for more than 3 months, whether primary or secondary, in cancer or non-cancer patients.
- Lymphoedema should be diagnosed by a trained specialist (vascular surgeon).

Diagnosis and Staging of Lymphoedema

Patients with established lymphoedema may require referral to other specialists to rule out malignancy or other illnesses. Patients with lymphoedema must be made aware that this condition will require lifelong self-management. The stage of lymphoedema should be determined by the specialist as it will be included in decisions on how the patient will be managed.

Stage 0 (Subclinical): A state where swelling is not evident despite impaired lymph transport. This stage may exist for months or years, for example in cancer patients, before oedema becomes evident. No excess limb volume is evident.

Stage 1 (Mild): Early onset of the condition where there is accumulation of tissue fluid that subsides with limb elevation. The oedema may be pitting at this stage. Excess limb volume is less than 20%.

Stage 2 (Moderate): Limb elevation alone rarely reduces swelling and pitting is manifest. Excess limb volume is 20-40%.
Late Stage 2: There may or may not be pitting as tissue fibrosis is more evident.

Stage 3 (Severe/Complex): The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowths develop. Excess limb volume is over 40%.

Management of lymphoedema

Stage 0 (Subclinical): patients such as cancer patients may be under the care of a specialist multi-disciplinary team.

Stage 1 (Mild): patients can be managed in primary care and community services.

Stage 2 and 3 (Moderate to very complex): patients should normally be treated by a lymphoedema specialist service (cancer centre or community services). See table below for management options according to stage of disease.

Management Table - British Lymphology Society Tariff (2013)

Staging of disease	Stage 0	Stage 1	Stage 2	Stage 3	Stage 3
Treatment Category	**Subclinical**	**Simple/ Mild** Lymphoedema with no complications requiring compression hosiery and education only	**Modified/Moderate** Lymphoedema requiring treatment then maintenance.	**Complex** Lymphoedema requiring intensive treatment	**Very complex** Lymphoedema requiring intensive and prolonged treatment
Treatment may include	6 monthly to yearly review	Supported Self-Management: • Skincare • Exercise • Simple lymphatic drainage • Education • Compression garment • Other	• Skincare • Exercise • Simple Lymphatic Drainage • Education • One element of CDT – MLLB, MLD, KT leading to a compression garment • Other	• Skincare • Exercise • Simple Lymphatic Drainage • Education • CDT leading to a compression garment • Other	• Skincare • Exercise • Simple Lymphatic Drainage • Education • CDT leading to a compression garment • Other
Treatment Schedule to include education	N/A	60 minutes (to include garment fitting)	30 minutes initial treatment 10 hours of modified CDT per area	30 minutes initial treatment 30 hours per area	30 minutes initial treatment Approx 100 hours. Treatment and length of treatment to be negotiated with the referrer before commencing.
Provider	Community nursing or cancer centre	Community nursing or cancer centre	Community nursing or cancer centre	Community nursing or cancer centre	Community nursing or cancer centre
Follow up First 12 months	6 monthly to yearly review	3 x 60 minutes (For example: 8 weeks, 6 months, 12 months)	3 x 60 minutes	3 x 60 minutes	To be negotiated according to length of treatment agreed
Ongoing Follow up Annually	6 monthly to yearly review	2 x 60 minutes until stable and /or discharged to the GP	2 x 60 minutes until stable and /or discharged to the GP	2 x 60 minutes until stable and /or discharged to the GP	Review and consider further treatment needed

Abbreviations

CDT: Complete Decongestion Therapy **MLLB**: Multi-Layer inelastic Lymphoedema Bandaging **MLD**: Manual Lymphatic Drainage **SLD**: Simple Lymphatic Drainage (self-massage) **KT**: Kinesio Taping (mimics effect of MLD)

Notes for management of lymphoedema
Individual plans of care that foster self-management will be developed in partnership with patients at risk of or with lymphoedema (involving relatives and carers where appropriate) in an agreed format and language. Self-management should include:

Stages 0 and 1:

- watchful waiting and review
- Skin care – to optimise the condition of the skin, treat any complications caused by lymphoedema and minimise the risk of skin infections
- Exercise/movement – to enhance lymphatic and venous flow
- SLD (self-massage) for swelling reduction and maintenance – to reduce limb size/volume and improve subcutaneous tissue consistency through compression and/or massage, and to maintain improvements
- Education – about how to self-manage lymphoedema and to avoid factors that may exacerbate lymphoedema (e.g. obesity)
- To learn how to apply, remove and care for compression hosiery

Stages 2 and 3:

- As above
- Patients undergoing intensive therapy must be carefully selected and be willing and able to commit physically and emotionally to daily intensive therapy, including participation in exercise programmes.

Body Mass Index

- The British Lymphology Society has reviewed the relationship between obesity and lymphoedema. Alternative lymphoedema treatment pathways have been proposed in order to provide the most effective treatment, within resources, for those patients with BMIs of 40 and above:
- Patients with a BMI equal to or above 40 (i.e. false lymphoedema) will have access to compression hosiery and weight loss advise. When BMI falls to below 40, they can then be referred for complete decongestive therapy (CDT). Patients with BMI over 40 with symmetric swelling may, if appropriate, have access to CDT or modified CDT.
- The Lymphoedema Network Northern Ireland have a detailed pathway for patients with a BMI equal to or greater than 40:

http://lnni.org/publications/lnnibariatricpolicy

References

1) International Society of Lymphology. The diagnosis and treatment of peripheral lymphoedema. Consensus document of the International Society of Lymphology.*Lymphology* 2003; 36(2): 84-91.
2) Best practice for the management of lymphoedema, International Consensus, 2013.
3) International Lymphoedema Framework (2006).
4) Clinical Resource Efficiency Support Team (CREST) Guidelines for diagnosis, assessment and management of lymphoedema, 2008.
5) CIGNA Guidance, 2013.
6) British Lymphology Society (BLS) Advisory Document, 2013.
7) BLS National Lymphoedema Tariff, 2013.
8) NICE Obesity Guidelines, 2006.
9) British Lymphology Society, Treatment pathway for patients with a BMI equal or greater than 40kg/m^2, 2013.