

HELPING PATIENTS SELF-MANAGE THEIR LYMPHOEDEMA

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This paper describes a matrix of service delivery for patients. The aim at each level is empowerment. The matrix describes five groups of patients with differing levels of lymphoedema complexity. The final group includes two groups of patients; those whose lymphoedema requires surgical intervention and children with lymphoedema. Treatment is used to facilitate the development of an expert patient who can move from a state of relative dependence to one of independence. This paper offers a model to facilitate planning and lymphoedema service provision.

Key words

Lymphoedema
Self-management
Commissioning
Chronic oedema

Lymphoedema is a chronic oedema caused by a failure in lymphatic drainage. It may be present from birth or in the very young (primary lymphoedema), or the swelling may occur later in life due to cancer or its treatment, infection, chronic venous insufficiency, or immobility.

Access to treatment is variable around the UK and people with a type of lymphoedema that is not cancer-related continue to struggle to access treatment (Morgan and Moffatt, 2007). The evidence around the incidence of cancer-related lymphoedema is limited, possibly due to methodological restrictions. Approximately 20% of breast cancer sufferers develop

lymphoedema (Clark et al, 2005), with a similar incidence for gynaecological cancers (Ryan et al, 2003). Incidence following treatment for malignant melanoma is quoted as between 23% and 80% (Williams et al, 1996).

There is some evidence to indicate that the number of people with lymphoedema swelling not related to cancer exceeds the cancer group by 3:1 (Moffatt et al, 2003). In this study, the prevalence of lymphoedema in the local population was found to be 1.33 per 1,000 for all ages, rising to 5.4 per 1,000 in the over-65 age group (Moffatt et al, 2003).

There are a small number of children and teenagers with lymphoedema. Worldwide, the estimated prevalence of lymphoedema in this age group is 1.15 per 100,000 (Smeltzer et al, 1985) — if this is extrapolated to the UK, there may be around 1,800 young people in the UK with lymphoedema.

Background

The matrix described in this paper was produced in response to a request by the Yorkshire Cancer Network to provide a document that could be used by potential commissioners of lymphoedema services. The model detailed in this article relates to all patients with chronic oedema — both cancerous and non-cancerous —

and is based around the objective of empowering patients to manage this chronic condition themselves. It follows on from work previously undertaken by the British Lymphology Society (BLS) and the International Lymphoedema Framework Project (BLS, 2001b; Lymphoedema Framework, 2006).

The matrix used here groups patients into five categories and is aligned with workforce and treatment requirements as well as outcomes for measuring effectiveness. Unlike previous work (BLS, 2001b; Lymphoedema Framework, 2006; Clinical Resource Efficiency Support Team [CREST] Guidelines 2008), there is a fifth category that addresses the needs of individuals with highly complex needs, including children and those requiring surgery for treatment of their lymphoedema.

This matrix is offered as a model to facilitate planning and service provision, however the authors acknowledge that work on this subject is an evolving process that will require regular review and updating.

The matrix

This matrix was developed after collaboration with service users, commissioners, service managers and a multidisciplinary group of members of the BLS.

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Table 1

Service requirements based on lymphoedema groups in the matrix

Group	Treatment required
1: At-risk	First appointment only
2: Mild/moderate swelling with no shape distortion	First appointment and three follow-ups Discharge with OT garments on repeat prescription If lymphoedema is on the leg, the patient may need further appointments for review of ankle brachial pressure index (ABPI) Oedema in advanced cancer: some patients have immediate care needs that can be treated by key workers who can provide home visits if required to assess and show carers programme of care Palliative lymphoedema needs: shared care required with primary care team. If there is ulceration, treat in primary care prior to lymphoedema treatment (palliative/modified lymphoedema bandaging)
3: Complex, one limb	First appointment; 15 sessions of decongestive lymphatic therapy (DLT); three follow-up appointments Discharge when stable and independent in made-to-measure garments provided through repeat prescriptions Oedema in advanced cancer: specialist input may be required to assess and reassess complex pathology in a rapidly changing situation and to advise on care programme. Specialised treatment close to home may also be required Palliative care: patients requiring daily care will need access to daily input through community-run service or treated as an in-patient
4: Complex, multiple limbs	First appointment; 21 sessions of DLT; three follow-up sessions Discharge patient when stable in made-to-measure garments provided through repeat prescriptions Oedema in advanced cancer: specialist input may be required to assess complex pathology in a rapidly changing situation and to advise on care programme. Specialised treatment close to home may also be required Palliative care: patients requiring daily care will need access to daily input through community-run service or treated as an inpatient
5: Surgery/ paediatrics	<p>Surgery Work-up requires DLT programme as per Group 3 One week hospital stay Five follow-up appointments in year one Two follow-up appointments in year two One follow-up appointment in years 3–5 OT garments on repeat prescription</p> <p>Paediatrics Parallel assessment by multidisciplinary team Parents or carers involved in provision of DLT Frequent appointments — usually four per year</p>

The matrix provides a breakdown of provision and costs and may be a valuable tool in developing a nationally agreed tariff for lymphoedema services. It was used to establish and agree a local tariff for patients referred to the Leeds Lymphoedema Service.

The role of self-management in the treatment of lymphoedema has already been described in previous publications (BLS, 2002; Lymphoedema Framework, 2006; CREST, 2008), and early identification and treatment can reverse and prevent the complications that result from this chronic condition, including swelling, pain, cellulitis, psychosocial morbidity and loss of function.

If patients can learn how to self-manage their condition, they reduce their dependence on other services, such as GP visits and hospital admissions. However, in some cases, immobility, obesity and chronic venous disease result in complex chronic oedema, of which lymphoedema is one contributing factor. People who are morbidly obese or who have skin ulceration often do not achieve good outcomes because of their age and/or physical condition, which means that they cannot become self-managing and are unable to undertake their own treatment.

The services detailed in this document focus on the treatment of individuals with lymphoedema who can either be aided to self-manage their condition or who are in a healthcare or family setting where others can assist with their management. This involves a progression from a state of relative dependence to one of independence. This is, in some ways, a reversal of the patient pathway described in the National Institute for Health and Clinical Excellence (NICE) guidance *Supportive and Palliative Care* (NICE, 2004), where there is an increasing need for services and support as the patient's health declines. However, in this matrix there is a reducing need for treatment and support as the aim is to help patients manage their own condition.

The increased availability of compression garments on the drug tariff means that a large proportion of patients can be discharged after a programme of treatment. Patient independence is facilitated by education and the provision of information, both for service users and clinicians. All clinicians who have contact with patients require information to aid identification, onward referral and provide early advice (BLS, 2001b).

Primary care team members (including GPs and district nurses) require education on how to support patients when they become self-caring (including the provision of repeat garments and reviewing discharged patients, including their vascular status). Agreed strategies are needed to treat patients with palliative lymphoedema and this often involves teamwork between primary care teams (e.g. district nurses, tissue viability nurses) and lymphoedema services. Although in many cases lymphoedema management is focused around self-care strategies, some patients require specialist care closer to home (Department of Health [DH], 2008). Using the staged approach within this matrix, commissioners and providers can agree a pathway for service delivery using appropriately trained professionals.

In practice

There are five patient groups as defined in groups 1–5 of the matrix (Table 1). It is anticipated that those patients at-risk, or with mild to moderate lymphoedema will become self-managing (groups 1 and 2) and can then be discharged from the service.

Patients with palliative care needs and the groups with complex needs (groups 3 and 4) will achieve varying levels of independence, depending on the severity of their condition. Patients with palliative lymphoedema needs and oedema in advanced cancer will require a programme of shared care with clear treatment pathways involving primary

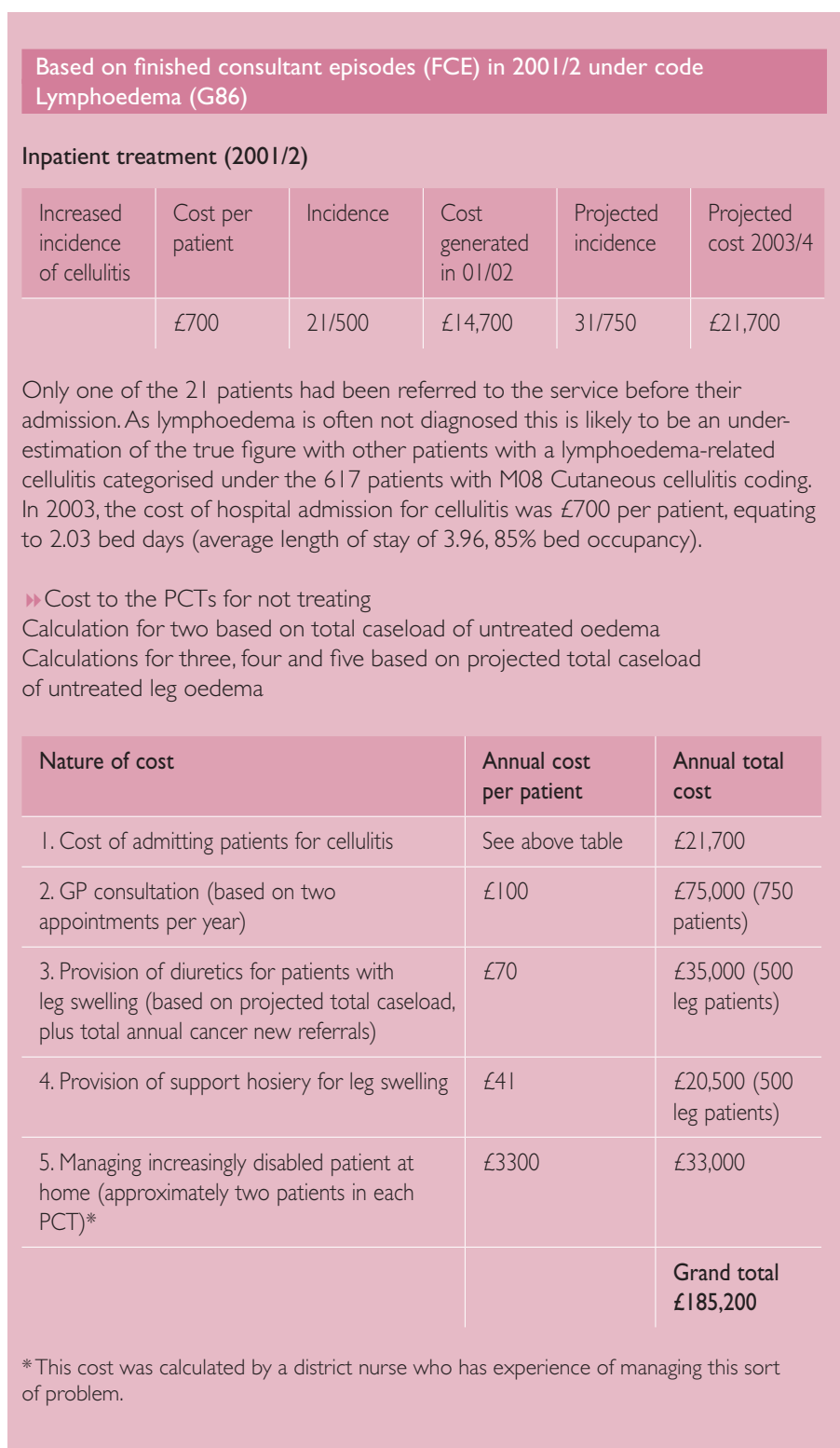


Figure 1. Cost of admitting patients for treatment of cellulitis.

care teams, lymphoedema clinics and social services.

The majority of patients will be successfully treated within groups 1–4. Around 1% will require a more specialised input.

Group 5 includes patients requiring surgical intervention or paediatric cases. Due to the small numbers involved, this facility could be offered on a regional basis. In some cases, the extreme fibrotic changes associated with chronic and non-pitting

lymphoedema can be reversed using surgery such as liposuction. Although compression garments continue to be required, the significant reduction in the size of the swelling can transform a person's psycho-social wellbeing as well as allow them to achieve economic independence (Brorson et al, 2008). The second group included in group 5 are paediatric lymphoedema cases who also require highly specialist care.

All patients will achieve independence in terms of knowledge about their condition and being able to make choices about their treatment options. Specific goals and outcomes are detailed in relation to each group within the matrix.

Implications of non-treatment

By commissioning a lymphoedema service, primary care trusts are fulfilling their requirements in relation to (DH, 2004 a, b, c; DH, 2008):

- ▶ Reducing inequalities through organisations working together
- ▶ Ensuring clinical and cost-effectiveness and making sure care is personal and safe
- ▶ Providing accessible and responsive care
- ▶ Delivering more information and choice.

In addition to these incentives, another consideration is the hidden cost attached to failing to treat a patient. Failure to treat results in a significant detrimental burden, both to the individual and also to the healthcare service. Some indication of the cost of untreated lymphoedema can be drawn from work undertaken in Leeds in 2001/2002 (Figure 1). At this point, lymphoedema treatment was restricted to cancer patients only, leaving a severe shortfall in provision for lymphoedema associated with other causes. A healthcare cost was calculated based on number of hospital admissions (bed days) and increased workload (hours and GP attendances) for primary care teams. This was estimated at £185,000 per patient per year with an average of 2.03 bed days per hospital admission

for cellulitis (average length of stay of 3.96 days, at 85% bed occupancy). This figure does not include the cost to the individual or the state that may arise from an inability to work because of lymphoedema.

Summary of roles

All patients, irrespective of their lymphoedema needs, will require education, treatment and support from specialist nurses and allied health professionals (AHPS) trained in conservative methods of treatment. Professional roles in lymphoedema services have already been described in an earlier Template for Management (Sneddon, 2007).

The model of service delivery described in this matrix shares common features with the BLS document (BLS 2001a, b), with different levels of knowledge and skills recommended for each of the five levels of care. Whereas the majority of services will require individuals trained to manage groups 1–4 of the matrix, it is recommended that the small number of service users in group 5 are treated in regional centres by highly specialist teams.

The roles and qualifications of staff described in the matrix are:

- ▶ Physiotherapist, nurse consultant (Skills for Health career framework 8a/b) or medical doctor — to act as strategic and clinical lead of the service. Clinicians at this level would need to assess patients and be responsible for medical work-up prior to treatment. They would supervise and take the main role in treating patients with complex needs (including individuals with complex palliative needs), lead the research programme and plan and deliver educational programmes. They would need to be educated to PhD or medical degree level
- ▶ Clinical nurse specialist/senior physiotherapist (Skills for Health level 6/7) — to deliver and coordinate specialist assessments and interventions and act as team leader for the specialist nurse team. They would also need to monitor

the budget. They would need to be educated to postgraduate degree (Masters) level

- ▶ Keyworker (nurse/physiotherapist) (Skills for Health level 5) — to assess and treat patients with mild/moderate lymphoedema and those with palliative needs, especially where treatment programmes can be taught to other carers. They will deliver and coordinate review clinics and monitoring. They would need to be educated to degree level
- ▶ Nursing/healthcare assistant (Skills for Health level 2–4) — to assist trained staff in the provision of treatment clinics, compression hosiery and printed/visual resource materials. Educated to NVQ level 3/2 depending on specific role within the team
- ▶ Administration staff to include secretarial support and a clinic clerk.

Patients in level 5 of the matrix will also require the input of a surgical team (plastics and/or vascular) in addition to the nurse/therapy team.

Selecting patients

Patients who are not willing to comply with their programme of care are unlikely to gain any long-term benefit from treatment.

In some cases, individuals may have medical problems that contraindicate treatment, although lymphoedema services may be needed at a later stage once the medical condition is treated and controlled. This includes individuals who:

- ▶ Have had a deep vein thrombosis (DVT) in the last three months
- ▶ Have untreated/undiagnosed/suspected malignancy (patients undergoing cancer treatment may be seen and given a modified management plan until they have completed their cancer treatment)
- ▶ Have severe or unstable cardiac failure — the nature of lymphoedema treatment is such that extra fluid is likely to be pushed into the circulatory system
- ▶ Have severe or unstable renal failure.

Individuals in these groups may require lymphoedema treatment as part of their care programme, which also involves other healthcare professionals and/or carers.

Other patient groups who may benefit from a model of shared care include:

- ▶ Individuals with chronic oedema who are unable to apply or remove compression garments, or who do not have access to carers. Patients who are referred should be assessed and given information and advice. The patient will then be discharged back to the care of the primary care team involved with advice and recommendations regarding the management of lymphoedema
- ▶ Individuals with existing leg ulcers
- ▶ Individuals with morbid obesity, i.e. body mass index (BMI) >40. High body weight may mean that these patients cannot manage self-treatment and often do not maintain any positive results, either due to poor treatment adherence or difficulty in obtaining adequate compression (e.g. deep skin folds often result in adipose tissue absorbing the sub-bandage pressure). All patients with a BMI of >30 are encouraged to follow a healthy eating programme. They are offered an initial appointment and assessed in the context of other criteria, especially their intention to adhere to the treatment programme, willingness to lose weight and the availability of support.

Indications for patients at level 5

There are some unique indications for paediatric and surgical patients:

- ▶ Surgery — unilateral non-pitting lymphoedema in adults when conservative therapy does not provide an acceptable option for long-term management. Patients undergoing liposuction must be prepared to continue with the long-term use of compression garments. At the present time, surgical treatment is not available in England although there is one

surgeon in Scotland. The expertise and structure for the delivery of microsurgical reconstruction is not available within the UK at the time of writing

- ▶ Paediatric service — children must be under the age of 18 years.

Treatment provision

Table 1 provides an indication of the level of input and treatment required for individuals within each group listed in the matrix.

Hours of service

Patients in groups 1–4 are provided with full contact details for the service, including address, telephone, fax number and email details. The lymphoedema service is open 52 weeks per year and for eight hours each weekday. An answerphone is available for out-of-hours messages.

Children and their families who fall under group 5 also have access to an extended telephone/email advice service. Adults may require inpatient care before and during their surgical treatment.

Outcomes

Details of outcomes for each category are detailed within the matrix. In essence, outcomes can be audited within the context of four main groups:

- ▶ Outcome information generated by service-users (e.g. satisfaction surveys, complaints, focus group feedback)
- ▶ Clinical governance of service delivery and education (standards, procedures, policies, protocols)
- ▶ Quantitative outcomes of treatment (e.g. limb volume measurements, health-related quality of life measurements, incidence of cellulitis, pain scores)
- ▶ Evidence of activity (number of referrals/discharges, frequency of treatment provided).

Relationships with internal and external stakeholders

Any service will need to have good communication links with a number of stakeholders. Some groups of

patients are unlikely to be able to self-treat and in some cases will need a long-term pathway of shared care provided by members of the primary or palliative care team. In other cases, partners or family members can become involved in daily care and will require comprehensive information and supervision as they develop their knowledge and skills.

The following may be involved in the provision of care:

- ▶ The service user, their partner or family
- ▶ Secondary care clinicians including those from oncology, dermatology, vascular, cardiac, renal, plastics and obesity specialty units. Other clinicians based within secondary care who may become involved include physiotherapy, clinical psychology, occupational therapy, dieticians, surgical appliances, podiatry, diabetes and tissue viability specialists. The service should also have established links with the nuclear imaging department and radiology for access to ultrasound diagnostic services
- ▶ Those units that provide services for children will have to maintain close contact with paediatric departments, including a specific paediatrician, geneticist, clinical psychologist and play specialist
- ▶ Links in primary care include district nursing teams, GPs and community services including obesity management, tissue viability, podiatry and physiotherapy
- ▶ Links with social services, including teams offering home care support and residential care facilities
- ▶ Specialist care providers, including palliative care and hospice provision
- ▶ Voluntary sector services, including those offering support or advice to service users and their families
- ▶ Charities and patient support groups
- ▶ Transport services
- ▶ Primary care trust commissioners.

Clinical governance

Any service should reflect standards set out by the BLS (2002) and the Lymphoedema Framework (2006).

These standards should include:

- ▶ Written guidelines incorporating the Governance Framework should be included in any service documentation and staff should be made aware of the standards against which the service will be assessed. Guidelines should include:
 - Standards for practice
 - Written guidelines for the safe provision of care
 - Written guidelines covering communication between clinicians and patients
 - Patients and carers should be regularly updated about any issues relating to clinical governance and the results of local or national audits
- ▶ Health and safety, e.g. staff/patient ratio; staff safety on home visits, etc
- ▶ Manual handling — clinic settings/home visits/obese patients
- ▶ Documented risk assessments
- ▶ Identified service lead/lead clinician
- ▶ Audit, to include:
 - Activity
 - Patient satisfaction
 - Outcomes
 - Complications
 - Compliance with targets
- ▶ Patient/public involvement:
 - User groups, to seek patient/carer and staff views
 - Openness with results of audits
 - Support groups: patients should be given details of relevant support groups early on in their pathway
 - Patient information: patients and carers should be provided with comprehensive information, which is clear and concise (patient information toolkit). Information should be made available in a wide variety of formats and should be clear, understandable, culturally sensitive and evidence-based. Any information given verbally should be precisely documented and backed up where appropriate with written literature.

Conclusions

This matrix for lymphoedema service development is offered as a model to facilitate planning and service provision.

However, the authors acknowledge that this is an evolving process that will require regular review and update. It is based on previous definitions and frameworks provided by the BLS, however there is an additional fifth group to address the specific needs of patients with complex needs requiring surgery and children with lymphoedema.

This matrix can be used in the commissioning of services for all patients with chronic oedema, with both non-cancerous and cancer-related causes. It may also provide a basis for establishing a range of tariffs for lymphoedema services. **JL**

References

- British Lymphology Society (2001a) *Framework for Education*. BLS, Sevenoaks, Kent
- British Lymphology Society (2001b) *Chronic Oedema Population and Needs*. BLS, Sevenoaks, Kent
- British Lymphology Society (2002) *Strategy for Lymphoedema Care*. BLS, Sevenoaks, Kent
- Brorson H, Ohlson K, Olsson B et al (2008) Controlled compression and liposuction treatment for lower extremity lymphoedema. *Lymphology* 41: 52–63
- Clark B, Sitzia J, Harlow W (2005) Incidence and risk of arm oedema following treatment for breast cancer: a three-year follow-up study. *Quart J Med* 98(5): 343–8
- Clinical Resource Efficiency Support Team (CREST) (2008) *Guidelines for the Diagnosis, Assessment and Management of Lymphoedema*. CREST, Northern Ireland
- Department of Health (2004a) *The NHS Knowledge and Skills Framework*. DH, London
- Department of Health (2004b) *NHS Improvement Plan*. DH, London
- Department of Health (2004c) *Standards for Better Health*. DH, London
- Department of Health (2008) *Darzi Report: High Quality Care for All: NHS Next Stage Review Final Report*. DH, London
- Lymphoedema Framework (2006a) *Best Practice for the Management of Lymphoedema*. London: MEP Ltd. Available online at: www.woundsinternational.com/journal.php?contentid=127
- Lymphoedema Framework (2007) *Template for Management: developing a lymphoedema service*. MEP, London
- Morgan PA, Moffatt CJ (2007) *Making the Case for Developing a Lymphoedema Service*. Available online at: www.mepltd.co.uk/oneoffsdetail.html?p=dls (accessed 15 February, 2010)
- Moffatt CJ, Franks P, Doherty DC (2003) Lymphoedema: an underestimated health problem. *Quart J Med* 96(10): 731–8
- National Institute for Health and Clinical Excellence (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. NICE, London.
- Ryan M, Stainton MC, Slaytor EK, et al (2003) Aetiology and prevalence of lower limb lymphoedema following treatment for gynaecological cancer. *Aus NZ J Obstet Gynaecol* 43(2): 148–51
- Smeltzer DM, Stickler GB, Schirger A (1985) Primary lymphoedema in children and adolescents: a follow-up study and review. *Pediatrics* 76(2): 206–18
- Sneddon M (2007) *Roles in Lymphoedema Services*. London, MEP
- Williams AE, Bergl S, Twycross RG (1996) A five-year review of a lymphoedema service. *Euro J Cancer Care* 5(1): 56–9

Key points

- ▶ The matrix describes five groups of patients, based on varying levels of lymphoedema complexity.
- ▶ The treatment objective in each group is helping people with lymphoedema to successfully self-manage their condition.
- ▶ Patients with advanced cancer or palliative needs are often able to self-manage and in this case, shared care programmes are agreed with either family members or health care workers.
- ▶ The matrix offers a model to facilitate planning and lymphoedema service provision.