

# ACHIEVING INDEPENDENCE THROUGH SELF-MANAGEMENT

Jacquelyne Todd

Lymphoedema is a debilitating and chronic condition for which there is no curative treatment (Lymphoedema Framework, 2006).

A combination of physical therapies are used to reduce and control the effects of lymphoedema and this may include daily treatment (decongestive lymphatic therapy — DLT). There is a strong argument that evaluation of care should address long-term outcomes that are measured after the initial course of treatment. Long-term success can only be achieved if the individual is able and confident to self-manage their condition. This will usually mean self-management on a daily basis — be it a skin care routine, regular exercise, or vigilance in care of the at-risk limb.

If individuals are unable to do this, treatment results cannot be sustained and any initial improvements will be lost. This could, in turn, result in more swelling and cause the individual to lose motivation and confidence in their ability to self-manage the condition. The matrix for lymphoedema service development (see pp. 91–96) is designed to help service providers to work with patient groups with differing levels of complexity in their condition. The aim is to facilitate independence in service users and provide them with the skills and knowledge to successfully self-manage their condition.

From the point of service provision, the skills and methods required in this process of empowerment will depend on the level of severity and the stage at which patients are referred to the service.

Jacquelyne Todd is a Physiotherapist Consultant in Lymphoedema, Lymphoedema Department, Leeds Teaching Hospitals NHS Trust

For example, although there will be some common ground, the needs of someone with mild arm lymphoedema will differ from those with severe leg lymphoedema, or an individual with oedema as a result of advanced malignancy. In addition to clinical expertise, patient groups will need other support structures in terms of educational and self-help resources, as well as access to a team of therapists and members of the multidisciplinary team. In some cases, patients themselves are unable to self-manage their condition, and here, education and resources are targeted at carers.

The matrix for lymphoedema service development is based on the earlier recommendations set out by the British Lymphology Society (BLS, 2001, 2002). It also addresses the needs of specific complex groups of patients, including children with lymphoedema and patients whose lymphoedema treatment includes the use of surgery.

The benefits of an effective self-management programme are illustrated in the conclusion of a service user: 'With appropriate self-care, our "new normal" can be a great and fulfilling life' (Dweck, 2009). To achieve this, the service user requires support with timely and relevant information and access to treatment services. Although there is some perceived improvement over the last decade, there is still evidence that many patients have difficulty in obtaining a diagnosis and effective treatment (Lam et al, 2006).

One of the challenges facing commissioners of lymphoedema services is the lack of a comprehensive framework by which to identify and evaluate the level of care that is required. Although there are similarities in the

types of complexity to be treated and the challenges to be addressed, requirements may differ depending on local prevalence and pre-existing services. The matrix for lymphoedema service development sets out what is needed for service delivery at each level of complexity, and is designed to help commissioners and service providers identify the skills and structure needed to treat lymphoedema. Variations in the quality of care delivered across England were highlighted in the Darzi Report (2008). Personalised care plans are described as one way of achieving high quality care for all. In lymphoedema this involves working with the patient to agree a self-management approach that is achievable and can be sustained. The matrix sets out a structure by which this can be delivered and evaluated, utilising both the results of treatment and also long-term outcomes that reflect the transition from dependence to independence on the part of the service user. This tool may be of value in facilitating service delivery both nationally and internationally. JL

## References

- British Lymphology Society (2001) *Chronic Oedema Population and Needs* (2nd edn). BLS, Sevenoaks, Kent
- British Lymphology Society (2002) *Strategy for lymphoedema care*. BLS, Sevenoaks, Kent
- Lymphoedema Framework (2006) *Best Practice for the Management of Lymphoedema*. International Consensus. MEP Ltd, London
- Dweck JA (2009) Finding my 'new normal' by self-empowerment and self-care. *J Lymphoedema* 4(2): 77–9
- Lam R, Wallace A, Burbridge B, Franks P, Moffatt C (2006) Experiences of patients with lymphoedema. *J Lymphoedema* 1(1): 16–21
- Department of Health (2008) *High Quality Care For All – Next stage Review Final Report*. DH London