Chronic Conditions Management (CCM) is a key priority in the five year Service Financial and Workforce Framework which we are developing. Lymphoedema is a chronic debilitating condition and affects individuals physically, psychologically and socially. Currently there is a wide variation in the organisation and delivery of services across Wales with many sufferers unable to access appropriate diagnosis and treatment and some only being able to access services as a result of having cancer.

It is for this reason that I requested the Welsh Association of Lymphoedema Services (WALS) to develop a strategy to help improve patient access to services, ensuring that the right treatment is provided by the right professional in the right place at the right time, whether it be for cancer or non-cancer related lymphoedema. Your predecessor organisations will have had the opportunity to comment on the draft Strategy, as part of the consultation process. I am now enclosing a copy of the final Lymphoedema Strategy.

The purpose of this Ministerial Letter is to ask you to firstly, review any current plans to limit or cease existing lymphoedema services and ensure existing services are protected. Secondly, I require your LHB to develop a lymphoedema delivery plan, by the end of March 2010 that maps the necessary activity and milestones to achieve the Strategy’s Key Actions, which are designed to lead to equity of access to high quality services across Wales. These delivery plans must ensure that lymphoedema services are given priority within LHB planning systems for CCM and the development of community services. Your LHB will need to map current lymphoedema service provision, develop the delivery plan, benchmark against
other LHBs and monitor and report to the Welsh Assembly Government on delivery of equitable lymphoedema services.

The underpinning planning assumption has to be that implementation must be funded from within the annual LHB funding allocations. I will however require you to consider the cost implications of implementing this Strategy and provide detailed advice to me, by 31 December 2009, providing profiled expenditure in line with the key actions, over the period of the Strategy.

Consequently, the 7 LHBs are required to collaborate to fund the appointment of an all Wales Project Manager, over a two year period, to help drive forward the implementation of the Lymphoedema Strategy and take forward the all Wales Key Actions, such as developing care pathways.

Paul Williams will write to the LHB Chief Executives setting out in more detail what is required and by when. I would ask that you ensure your LHB gives due priority to implementing the Lymphoedema Strategy and improving access to and the quality of care to meet patient need effectively.
Strategy for Lymphoedema in Wales

Designed for Lymphoedema
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Executive Summary

Lymphoedema is a chronic swelling due to lymphatic system failure. It can occur from a congenitally determined lymphatic abnormality or from lymphatic damage by inflammation, infection, trauma, tumour, surgery or radiation. It is chronic and incurable and requires lifelong management. Lymphoedema can affect people of all ages and can occur in a limb, limbs, in the head and neck, trunk or genital area. It may not become apparent for sometime after the initial trauma or surgery and patients remain at risk of developing lymphoedema for the remainder of their lives. Lymphoedema affects individuals physically, psychologically and socially. It has a significant impact on quality of life and the ability to undertake normal activities of daily living.

Currently there is wide variation in the organisation and delivery of lymphoedema services across Wales. Some Local Health Boards provide full lymphoedema services; others offer services that can only be accessed by cancer patients and then there are certain areas that do not provide any services. Clinics range from lone practitioners to small teams; some with administration support others without. Waiting and treatment times vary as well as treatment options. This vast diversity is not a result of patient need and is not patient centered. Most people with lymphoedema go undiagnosed and untreated for long periods of time. This is a consequence of the poor level of knowledge amongst health professionals and the public of this disease.

Based on the prevalence of lymphoedema found in the South West London study of 1.33 per 1,000 there would be an estimate of 4,000 lymphoedema sufferers in Wales. However, looking at the prevalence rates for the last 5 years in the established Welsh clinics shows a rise every year and the average is well over 2 per 1,000. Thus in Wales with a population of 2.9 million at least 6,000 people will have lymphoedema.

The Welsh Assembly Government is committed to ensuring evidence-based service provision, underpinned by national and professional standards, to address the health needs of the 21st Century. The Strategy for Lymphoedema in Wales outlines a vision for Welsh lymphoedema services to improve well being, minimise the risks associated with lymphoedema, ensuring that patients can access the right services, while empowering them to maximise their own independence. This will require the delivery, development and planning of lymphoedema services where care is proactively planned and coordinated.

This vision will be delivered by promoting healthy lifestyles, encouraging lymphoedema prevention and adhering to evidence based practice as well as professional guidelines and standards.

The main aims of the Lymphoedema Strategy are;

- Raise awareness of lymphoedema and how simple treatment strategies can improve patients’ quality of life.
Improve health and well being by empowering patients to maximise their own independence and minimise the risks associated with lymphoedema.

Integrate, develop, reconfigure and more effectively plan and manage lymphoedema services throughout Wales.

Improve patient access to lymphoedema services ensuring that patients receive the right treatment at the right time by the right professional in the right place.

Provide a comprehensive preventative approach to all patients at risk of developing lymphoedema thereby reducing the demand on other NHS services.

Build on the strengths of the current tertiary and secondary care lymphoedema services integrating services across organizational boundaries incorporating community, primary care and social services.

Develop and build on the current available lymphoedema education enabling health care professionals to access local courses easily to implement in their own practice.

Identify the actions needed to implement lymphoedema services across Wales and improve service delivery.

Each Local Health Board must establish or improve dedicated lymphoedema services in their localities. Specialist lymphoedema services must be placed within the hospital setting with community clinics or hospitals providing less complicated management and ongoing monitoring of patients with mild forms of this chronic condition. Establishing lymphoedema services does not only improve patient quality of life but decreases other associated health care costs including reducing hospital admissions for cellulitis. Neglecting chronic oedema/ lymphoedema ultimately results in a massive drain on NHS resources.

Each Local Health Board must have a nominated lead lymphoedema professional that will ensure protocols, care pathways and standards of lymphoedema are being met. This enables patients to receive standardised appropriate treatment bringing an end to current inequity of service provision. The lead professional will work to improve communication, clinical supervision, support, retention, audit, education, research and will ensure clinical governance standardisation.

Key issues, case studies and other solutions for improving the management of lymphoedema are highlighted throughout this document to aid planning decisions. A number of key actions are also identified at the end of each chapter to ensure a more equitable and consistent approach to service provision across Wales.

This document is aimed at planners of health and social care services, providers of statutory, voluntary and independent services and individuals living with lymphoedema as well as their families and carers. A whole system approach is required to
strengthen partnership working across traditional organisational and professional boundaries to ensure care can be provided in the most appropriate and effective way.
Key Actions

1. Implement a lymphoedema project manager
A two year post, funded by the 7 Local Health Boards, is to be established to coordinate and work alongside Local Health Boards in the planning and delivery of new and existing lymphoedema services. It will guarantee that service specifications including referral criteria, discharge protocols and collaboration procedures are identical throughout Wales ensuring equity of access for all lymphoedema sufferers. The post will also coordinate education, audit and data collection and take forward the proposals in this document.

2. Set up a lymphoedema clinical network
A Welsh network of lymphoedema services should be established. Patients with primary and non-cancer related lymphoedema should have equal access to the service. A Lymphoedema planning and delivery group should be established with robust links with the core chronic conditions management and community services development groups in Local Health Boards.

- **Specialist Led Lymphoedema Clinics**: Specialist lymphoedema clinics should be developed at:

<table>
<thead>
<tr>
<th>LHB</th>
<th>Base</th>
<th>Operational</th>
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<tbody>
<tr>
<td>Betsi Cadwaladr</td>
<td>o Wrexham Maelor Hospital</td>
<td>o Established</td>
</tr>
<tr>
<td></td>
<td>o North Wales Cancer Centre, Glan Clwyd</td>
<td>o Established</td>
</tr>
<tr>
<td></td>
<td>o Eyri Hospital Caernarvon</td>
<td>o Established</td>
</tr>
<tr>
<td>Powys</td>
<td>o <strong>Brecon War Memorial Hospital or Bontlys with clinics at Newtown Hospital and Llandrindod Wells</strong></td>
<td>o <strong>Not fully established</strong></td>
</tr>
<tr>
<td>Hywel Dda</td>
<td>o Prince Phillip Hospital Llanelli</td>
<td>o Established</td>
</tr>
<tr>
<td></td>
<td>o Withybush Hospital</td>
<td>o Established</td>
</tr>
<tr>
<td></td>
<td>o <strong>Bronglais Hospital, Aberystwyth with clinics in Cardigan/ Newcastle Emlyn</strong></td>
<td>o <strong>Not fully established</strong></td>
</tr>
<tr>
<td>Abertawe Bro Morgannwg</td>
<td>o Singleton Hospital, Swansea</td>
<td>o Established</td>
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<tr>
<td></td>
<td>o <strong>Princess of Wales Hospital Bridgend</strong></td>
<td>o <strong>Not established</strong></td>
</tr>
<tr>
<td>Cwm Taf</td>
<td>o Royal Glamorgan Llantrisant</td>
<td>o <strong>Not established</strong></td>
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<tr>
<td></td>
<td>o Prince Charles Merthyr</td>
<td>o <strong>Not fully established</strong></td>
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<tr>
<td>Cardiff and Vale</td>
<td>o University Hospital of Wales</td>
<td>o <strong>Not established</strong></td>
</tr>
<tr>
<td></td>
<td>o Llandough Hospital</td>
<td>o <strong>Not established</strong></td>
</tr>
<tr>
<td>Aneurin Bevan</td>
<td>o St Woolos Newport</td>
<td>o Established</td>
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<td></td>
<td>o <strong>Neville Hall, Abergavenny</strong></td>
<td>o <strong>Not fully established</strong></td>
</tr>
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* The South East Wales lymphoedema service hosted by Velindre Hospital provides an under resourced lymphoedema service for the residents of Cwm Taf, Cardiff and Vale and Aneurin Bevan.
New services need to be created and additional qualified and unqualified staff must be incorporated into existing clinics. Trained lymphoedema assistants (Band 3) can maintain some of the mild/moderate lymphoedema cases developing specific skills such as monitoring and measuring limb circumference and teaching patients ‘Simple Lymph Drainage Massage’. This would empower patients in supported self care and support workforce planning. This ultimately frees up specialist time reducing waiting times for patients. Health Care Professionals should be trained to work closely with lymphoedema services becoming ‘Link workers’ in order that collaboration can occur with palliative and community house bound patients.

**Lymphoedema Practitioners**- Reviewing the prevalence figures Wales needs 27.3 WTE qualified lymphoedema specialist/practitioners working to the agreed guidelines, care pathways and protocols. Lymphoedema practitioners can be from a variety of healthcare backgrounds but are often registered nurses or physiotherapists. In each of the lymphoedema clinics a suitable qualified skill mix would be employed ranging from a Band 5 to a Band 8a. 18.3 WTE posts already exist thus an additional 9 WTE are needed.

**Lymphoedema Assistants**- Employing lymphoedema assistants and administration staff will free up lymphoedema practitioners’ time from more routine duties and assist in the data collection. Wales requires 17.6 WTE lymphoedema assistants and administration posts to support lymphoedema services. Lymphoedema assistants are usually healthcare workers with a level 2/3 NVQ and clerical/secretarial staff. We currently only have 5.6 WTE assistants thus an additional 12 WTE are necessary.

In addition to the specialist lymphoedema clinics, services should develop local clinics in community hospitals, GP surgeries or clusters. This is especially important in rural settings. Collaboration with primary and community staff is vital. Lymphoedema education must be supported so that all community staff are aware of the benefits of shared care. Lymphoedema service links must be developed with dermatology, vascular and tissue viability services. Collaboration and liaison will set firm foundations for delivery of joint clinics and supported care. Much can be learned from collaboration. Developing services alongside one another will truly provide patient centred services.

3. **Develop a lymphoedema prevention protocol for all services in Wales**

Prevention and early recognition are extremely important. Potential long term savings can be achieved through successful implementation of preventative programmes.

- All patients who are at risk of developing lymphoedema must be informed and given written and verbal information on how to minimise their risk.
- Specific prevention schemes to be established in each of the services i.e. Breast, gynaecological, melanoma, urological and head/neck cancer lymphoedema prevention schemes.
- All health care professionals to be made aware of the prevention strategies available for lymphoedema patients.
4. All patients suffering with lymphoedema / chronic oedema to be referred to a specialist lymphoedema service.
   - All patients must be referred promptly to their local lymphoedema service using an all Wales lymphoedema referral form. Adequate referral pathways must be in place so that referrals are appropriate and timely.
   - A complete physical and psychological assessment of all patients diagnosed with lymphoedema should be undertaken using an all Wales lymphoedema assessment form.
   - Pathways need to ensure ‘at risk’ patients or those with mild lymphoedema are transferred to trained ‘Link Workers’. ‘Link workers’ must complete a lymphoedema management course and maintain their skills. Preserving skills may be difficult in the community unless dedicated sessions are agreed and funded, financially; it may be more pertinent that lymphoedema health care support workers/assistants affiliated to lymphoedema services monitor these patients.

5. All lymphoedema services should offer a comprehensive lymphoedema treatment programme where daily intensive management is available if needed.
   - Treatment and management must be tailored to each individual patient’s needs, with appropriate review and reassessment. Daily intensive management (Decongestive Lymphoedema Therapy) consists of Manual Lymphatic Drainage (MLD), Multi Layer Lymphoedema Bandaging (MLLB), Simple Lymph Drainage (SLD), skincare and exercise must be available. Lymphoedema Specialists and Practitioners must be fully trained to be able to offer this treatment.
   - Patients must be involved in their lymphoedema treatment planning process and mutual goals set and adhered to.

6. All patients attending a lymphoedema service must be encouraged to self manage their chronic condition with support.
   - Patients feel more in control of their lymphoedema by performing simple tasks such as moisturising their skin and wearing compression garments.
   - User/support groups should be established within Local Health Boards. Patients should be encouraged to access Healthy Living Schemes, Expert Patients Programmes, and Macmillan Cancer Support etc.

7. Develop a lymphoedema education programme
   - Education on recognising lymphoedema/ chronic oedema should be incorporated into all healthcare professionals training.
   - An awareness programme must be undertaken to raise lymphoedema knowledge.
   - All lymphoedema services should develop lymphoedema link worker education sessions for healthcare staff who regularly come into contact with patients at risk of lymphoedema including community, dermatology, tissue viability and palliative care.
   - The lymphoedema specialists/ practitioners must be fully trained in lymphoedema management, via established courses.
   - An education and training needs analysis must be undertaken to determine the training required in each of the Local Health Boards. Partnerships with local universities to be pursued exploring accreditation of lymphoedema courses.
8. **Collection of clinical data is vital and all lymphoedema services in Wales should be using the LymCalc computer software programme.**

   Data collection on lymphoedema is inadequate throughout Wales. No universal or agreed data set is in existence thus patient needs, waiting times and demands on services are only done at a local level. Clinical data must be collected throughout Wales including the numbers of new, follow up, intensive treatments being undertaken. As lymphoedema is a chronic life long condition, data must be collected on the raising activity, level of discharges, deaths and clinical outcomes. This information should be linked to the LymCalc computer programme which could extract all the data required for audit, clinics and commissioners. This data can also be collected on actual lymphoedema incidence and prevalence as well as referral data in each of the Local Health Boards.

9. **Lymphoedema service data should be included in the NHS Wales Diagnostic and Therapy Services Waiting Times Targets.**

   Data on numbers of patients and waiting times needs to be addressed urgently. It has been suggested that lymphoedema services could be included in the NHS Wales Diagnostic and Therapy Services Waiting Times Targets. This would mean that no new lymphoedema patient should then be waiting longer than 14 weeks for an appointment if following the timescale for therapies. This could be audited and acted upon.

10. **Central purchasing of compression garments should be explored.**

    Financially, garments form a significant part of service costs thus adequate funding for compression garments and hosiery is essential. The costs of garments vary greatly depending on the extent and area of swelling. Negotiation is needed on compression garments throughout Wales as different services are charged dissimilar amounts. Clear protocols on issuing garments needs to be developed.
Chapter 1
Setting the Scene

1.1.1 Health care services are currently unsustainable with an over-reliance on historical, and often inappropriate, models of care. Action is needed to ensure resources used in primary and secondary care can prevent and decrease admissions to hospital, as well as promoting patient’s own self-care. Improvements to current lymphoedema services are necessary to ensure high quality care can be provided that is supported by a workforce for sustainable, primary and community based models of care.1

1.1.2 Currently there is wide variation in the organisation and delivery of lymphoedema services across Wales. Some Local Health Boards provide full lymphoedema services; others offer services that can only be accessed by cancer patients and certain areas do not provide services at all. Clinics range from lone practitioners to small teams, some with administration support others with no support staff. Waiting and treatment times vary as well as treatment options. This vast diversity is not a result of patient need and is not patient centered. This strategy will redress this variability to ensure lymphoedema services are accessible and equitable to all.

1.1.3 The main aims of the Lymphoedema Strategy are;

- Raise the awareness of lymphoedema and how simple treatment strategies could improve patients’ quality of life.

- Improve health and minimise the risks associated with lymphoedema as well as empowering patients to maximise their own independence.
Integrate, develop, reconfigure and more effectively plan and manage lymphoedema services throughout Wales.

Improve patient access to lymphoedema services ensuring that patients receive the right treatment at the right time by the right professional in the right place.

Reduce levels of morbidity and lymphoedema related disability.

Provide a comprehensive preventative approach to all patients at risk of developing lymphoedema thereby reducing the demand on other NHS services.

Build on the strengths of the current lymphoedema services integrating them across organizational boundaries supporting community and primary care.

Develop and build on the current available lymphoedema education enabling health care professionals to easily access local courses to implement in their own practice.

Identify the actions needed to execute lymphoedema services across Wales and improve service delivery.

1.1.4 This document is aimed at planners, developers and providers of health and social care services, in both the statutory and voluntary sectors and individuals living with lymphoedema, their families and carers. Its purpose is to improve the health, well-being and the quality of life for lymphoedema patients in Wales. It is supported by the ‘Model and Framework for Chronic Conditions Management’ which delivers a more proactive and planned approach to managing chronic conditions across Wales.¹

1.1.5 This document has been compiled in partnership with the Welsh Association of Lymphoedema Services (WALS) and its members. WALS was established in 2001 to help steer lymphoedema provision in Wales. It provides advice and support to healthcare professionals and others responsible for planning and funding services to ensure they are evidenced based to support the delivery of effective care for lymphoedema patients across Wales. This document has been built on the previous work undertaken to develop lymphoedema services in Wales led by Melanie Lewis and Eilish Lund and is based on the views of patients and health care professionals working in lymphoedema.

1.1.6 This document is needed to develop and improve lymphoedema services across Wales. Establishing lymphoedema services does not only improve patient quality of life but decreases other associated health care costs including decreasing hospital admissions for cellulitis. Neglecting chronic oedema/lymphoedema ultimately results in an immense drain on NHS resources.

1.1.7 Appropriate diagnosis and management of lymphoedema will significantly save money by reducing hospital admissions and avoiding inappropriate interventions. Frequently lymphoedema patients are referred from one speciality to another without actually being referred to a lymphoedema clinic for treatment. Gaining a diagnosis of
lymphoedema can also be difficult where patients are referred to numerous specialities for opinions, including vascular surgery, orthopaedics, plastic surgery and dermatology. Therefore patients are not seen by the right person, at the right time or the right place.

1.2 What is lymphoedema?

1.2.1 Lymphoedema is a chronic swelling due primarily to a failure of lymph drainage. It arises from a congenitally determined lymphatic abnormality or from damage to lymphatic structures by inflammation, including infection, trauma, tumours, surgery or radiation. It is chronic and incurable and requires lifelong management including psychosocial support. Lymphoedema can affect people of all ages. It can occur in a limb or limbs, in the head and neck, trunk or genital area. It may not become apparent for sometime after trauma (e.g. cancer surgery) and patients remain at risk of developing clinical lymphoedema at a later stage.

1.2.2 Lymphoedema can be classified as primary or secondary lymphoedema:-

Primary lymphoedema usually presents at puberty, rarely soon after birth. The first indication is usually swelling of the feet and ankles and is more predominant in women. Although less common than the secondary form it is often more extreme with disability being present for much of a patient's life.²

Secondary lymphoedema occurs as a consequence of disruption or obstruction of the lymphatic pathways. The most prevalent secondary lymphoedema worldwide is filariasis which is most common in South East Asia affecting 120 million people. In the UK, cancer surgery involving the lymphatic system, radiotherapy, trauma, vascular disease, cellulitis, immobility and dependency are the most common causes. The physical and psychological consequences are similar in patients with primary or secondary lymphoedema but, given the longer period of disability in primary cases the economic consequences are greater.

Cellulitis is both a cause and a complication of Lymphoedema. The occurrence of Lymphoedema varies between 10% and 19% amongst cases of Cellulitis with up to 50% of patients with Lymphoedema experiencing at least one bout of Cellulitis.³

1.3 What is the impact of lymphoedema?

1.3.1 Lymphoedema is well documented as being an extremely debilitating condition. Some people with mild lymphoedema can manage their condition on their own with little support from health care professionals. If their lymphoedema is controlled then they may only need to be reviewed once or twice a year for a check up and renewal of their compression garments. Other patients are less able to self manage and need intensive management to reduce, maintain and control their swelling, needing significant input from a multi disciplinary team. Lymphoedema is very changeable; a mild lymphoedema patient who is followed up every 6 months can suddenly become complex and may need intensive daily treatment to reduce their swelling.
1.3.2 Physical Impact-
- Swelling - difficulty finding shoes/clothes that fit/ inability to wear jewellery
- 50% of patients reported pain and discomfort due to their lymphoedema
- Reduced range of movement in specific joints and mobility
- Skin changes including hyperkeratosis, fibrosis and thickened skin folds
- Decrease in muscle strength and exercise tolerance
- Difficulty in performing activities of daily living
- Leakage of lymph fluid (Lymphorrhoea)

1.3.3 Psychological Impact-
- Many patients experience depression, anger and anxiety
- A feeling of helplessness and fearful about living with lower limb lymphoedema
- Significant impact on mental health
- Self esteem, self efficacy and self image may also be affected due to chronic pain
- Difficulties in social settings due to the stigma associated with their appearance and in opening up to their feelings with their family and friends
- Embarrassed how the effects of cancer or its treatment can impact on them sexually

“It must be noted that the psychological aspects of both primary and secondary lymphoedema are equally as important to treating the medical symptoms.”

Lymphoedema patient

1.3.4 Social- Economic Impact
- Patients with chronic oedema may become socially isolated as they are unable to interact with others, enjoy previous hobbies or work due to the debilitating swelling, decreased mobility or leaking lymph fluid.
- The overall economic impact of lymphoedema is considerable given the cost associated with health care provision, social welfare and lost income.
- Patients with lymphoedema should be signposted to advice and support available to help them deal with the financial impact associated with their condition. Macmillan Cancer Support can provide free information to patients whose lymphoedema is associated to cancer.

Lymphoedema caused 80% of patients within a catchment area to be off work, 9% to change their employment status, 2% to switch jobs and 8% to give up work entirely

1.4. Categories of lymphoedema

1.4.1 Lymphoedema can be staged or classified in order to distinguish the extent of the problem so that a successful realistic treatment plan can be devised. The two most common models of classification used are:

1. International Society of Lymphology (ISL) Lymphoedema Staging (2003) (Table 1)
2. British Lymphology Society (2001) (Table 2)
1.4.2 The ISL lymphoedema staging is classified according to physical signs associated with the appearance of swelling. Psychosocial and psychological aspects are not considered. A patient may enter at stage 0 (latency period) and stay in that category for many years whereas another patients may progress quickly from 0 to III due to severity of oedema.

The BLS classification which is widely used in the UK, does acknowledge quality of life issues. Although classification is useful sometimes patients cannot fit into one category and will move frequently between BLS groups 2 and 3 depending on how controlled the lymphoedema is.

Table 1 International Society of Lymphology (ISL) Lymphoedema Staging (2003) based on the German Society of Lymphology

| Stage 0/Latent | • The lymphatic vessels have sustained some damage which is not yet apparent. Transport capacity * is reduced but is still sufficient for the amount of lymph being removed  
• Subjective complaints from patient possible  
• No clinical evidence of lymphoedema, however a slower lymph flow is detected by lymphscintigraphy with initial dermal backflow  
• Lymphoedema is not present but patient is classified as being at risk from developing lymphoedema. |
| Stage I | • Oedema is present  
• Tissues are pitting, soft, and doughy  
• Swelling reduces with elevation  
• Little or no tissue fibrosis, negative Stemmer’s sign**. |
| Stage II | • Oedema is present  
• No reduction of swelling on elevation  
• Connective tissue proliferation/fibrosis  
• Pitting becomes more difficult  
• Positive Stemmer’s sign. |
| Stage III  
Lymphostatic Elephantiasis | • Fibrosis and sclerosis (severe non induration) pitting  
• Positive Stemmer’s sign  
• Hyperkeratosis  
• Lymphangioma  
• Papillomatosis  
• Fungal Infections. |

* Transport capacity of the lymphatic system refers to the amount of lymph which is transported by the lymphatic system utilising its maximum amplitude and frequency.

** Stemmer’s Sign is positive when a thickened skin fold at the dorsum of the fingers or toes cannot be lifted or is difficult to lift. The presence of this sign is an early diagnostic indication of lymphoedema. The absence of a Stemmer sign does not rule out the possibility of lymphoedema.
Table 2 British Lymphology Society (2001) classification of lymphoedema

<table>
<thead>
<tr>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>People at Risk</td>
<td>Mild uncomplicated lymphoedema</td>
<td>Moderate to severe/complicated lymphoedema</td>
<td>Oedema in advanced disease</td>
</tr>
<tr>
<td>- No clinical signs of oedema</td>
<td>- Excess limb volume &lt;20%</td>
<td>- Swelling present in the trunk, digits, or genitals</td>
<td>- Uncontrolled metastatic disease</td>
</tr>
<tr>
<td>- Risk factors for oedema can be identified</td>
<td>- No involvement in the trunk, genitals or digits</td>
<td>- Distorted limb shape</td>
<td>- Weeping/ulceration of affected limb</td>
</tr>
<tr>
<td></td>
<td>- Healthy intact skin</td>
<td>- Skin in poor condition</td>
<td>- Impaired function</td>
</tr>
<tr>
<td></td>
<td>- Normal shape</td>
<td>- Active or controlled malignancy</td>
<td>- Impaired mobility</td>
</tr>
<tr>
<td></td>
<td>- No venous or arterial complications</td>
<td>- Complications including cellulitis, Lymphorrhoea</td>
<td>- Impaired sensation</td>
</tr>
<tr>
<td></td>
<td>- No active malignancy</td>
<td>- Moderate lymphoedema excess greater than 20% but not more than 40%</td>
<td>- Pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Severe lymphoedema 40% or more</td>
<td>- Infection</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Oedema of the face, genitals, head or neck</td>
</tr>
</tbody>
</table>

1.5 The strategic context for services in Wales

1.5.1 The Review of Health and Social Services in Wales by Sir Derek Wanless and Sir Jeremy Beecham’s Review of Local Service Delivery have highlighted that new ways of working are needed to deliver health and social care services that are fit for purpose in Wales. The agenda to improve health services has been set in Wales, led by Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century.

1.5.2 The improvements needed to address the lack of dedicated lymphoedema services are extensive and complex. The Chronic Conditions Management Framework sets out how chronic conditions, like lymphoedema, must be managed in Wales. The Chronic Conditions Management (CCM) Service Improvement Plan - 2008-2011 identifies the actions needed to implement the CCM Model and Framework, improving prevention and the care of those living with chronic conditions as well as supporting people’s independence in all areas of life.
1.5.3 The Cancer Services Coordinating Group (CSCG) commissioned a second review into lymphoedema services in Wales and ‘A Review - Lymphoedema Services in Wales’ was published in July 2006. Its summary stated

- Lymphoedema sufferers are still being untreated and are not being managed effectively
- The lack of appointing an all-Wales lymphoedema project manager/ coordinator to integrate the services has led to little movement in the development of this Cinderella service
- Data collection is inadequate leading to inaccurate prevalence and incidence figures
- Significant shortfalls in appointing specialist and administrative staff
- Overall support in establishing an All Wales purchase of compression garments
- Improve the overall awareness of lymphoedema in the NHS
- Investigate whether the use of lymphoedema targets could be implemented

1.5.4 In October 2006 the ‘International Consensus Best Practice for the Management of Lymphoedema’ document was produced and distributed. Its main aim is to raise the profile of lymphoedema and improve patient access to care. In February 2008 the Clinical Resource Efficiency Support Team CREST published Guidelines for the Diagnosis and Management of Lymphoedema as well as a number of recommendations, it stated that:

‘Each NHS Trust should establish a dedicated lymphoedema service to identify and address the needs of patients with, or at risk of developing, lymphoedema.’

CREST 2008

Similarly, numerous NICE cancer guidelines have recommended access to lymphoedema services. Lymphoedema services must take account of any new or updated NICE guidance.

1.5.5 The Welsh Assembly Government is committed to achieving high standards across the public service as set out in Making the Connections. This emphasizes the need to design and operate services around the needs of the users, not the provider, taking into account all associated risks, and ensuring high quality, easily accessible and responsive services. Strategic level partnerships, working across all organisational boundaries, are needed to agree common goals, avoid duplication and support the sustainable development of effective and responsive services. Local Health Boards and future service planning arrangements will play an increasingly important role in this context.

1.5.4 The Lymphoedema Strategy is an issue for the whole of Wales. Implementation and development of lymphoedema services will be based on the assessment of local needs and existing service provision but must be consistent with the strategic direction outlined in this document. Plans to implement and commission the key actions in this document will need to be considered by the seven Local Health Boards and their partner providers, including the third sector in the development of local delivery plans.
1.5.5 This strategy will help patients at risk of lymphoedema or with primary or secondary lymphoedema have a diagnosis and treatment which is timely, effective, efficient, patient focused and with measurable outcomes.

1.6 Key principles and aims

1.6.1 This strategy focuses on the needs of people with lymphoedema and aims to ensure that:
- All patients suffering with lymphoedema or chronic oedema are given a diagnosis and referred to an appropriate local lymphoedema service.
- Patients with lymphoedema are referred for assessment in a timely manner as early intervention reduces the severity of lymphoedema.
- Patients diagnosed with lymphoedema become partners in their treatment management optimising self care and promoting independence.
- All patients experiencing lymphoedema are offered appropriate treatment strategies that are, where possible evidence based.

1.7 Planning and delivery of lymphoedema services

1.7.1 Robust planning and delivery will need to ensure that all lymphoedema services are evidence-based, patient-centred, accessible, cost effective and responsive to the needs of lymphoedema patients. Currently there is wide variation in the organisation and delivery of lymphoedema services across Wales. In Powys and Ceredigion there are no fully established lymphoedema services. In South East Wales lymphoedema service the non cancer lymphoedema referrals were accepted for a brief time, demand exceeded capacity with referrals being placed on a waiting list.

‘The provision of lymphoedema treatment facilities must take into account the reduction in mobility experienced by many lymphoedema patients. Local treatment facilities are ESSENTIAL’. Lymphoedema patient

1.7.2 Long term and sustainable services must be developed using local need acquired as an integral part of the planning and delivery process. This will inform the development of local services and the Health, Social Care and Well-Being Strategies in partnership with service users, their carers and all key stakeholders. Consideration should also be given to what clinical outcomes are relevant and important. Evaluation and audit must be supported by information technology wherever possible for example the use of the LymCalc lymphoedema software programme.

1.7.3 Local service users are essential in helping to determine how services can best meet their needs. Public and patient involvement including local support groups will need to be further developed to ensure patient’s experiences are discovered.
Chapter 2
Incidence and Prevalence of Lymphoedema
How common is it in Wales?

2.1 Background

2.1.1 In order to understand the impact of lymphoedema on a population it is important to have accurate information on the prevalence and incidence. However lymphoedema is a relatively newly recognised condition- the first Welsh service having been in operation for 14 years. This situation would lead to a lower prevalence figure and a higher than normal incidence as professionals’ awareness and referrals increase.

Adding to this is the difficulty that there is no agreed international definition of lymphoedema and many NHS staff do not recognise the condition. It might be argued though that lymphoedema was recognised but as no services were available that it was not documented and no treatment offered.

2.2 Literature search

2.2.1 Only one study so far has reported the incidence of lymphoedema in a defined population (SW London) This study found a prevalence of 1.33 per 1,000 for all ages, increasing to 5.4 per 1,000 in the over 65 age group. Only 63% of these patients were receiving treatment for their lymphoedema. The authors commented that their estimates were likely to considerably underestimate the problem. They concluded that lymphoedema was a common but under-reported condition with prevalence similar to leg ulceration. In relation to leg ulceration, there is a 10 per 1,000 lifetime risk of leg ulcers ranging from 1.5 to 3 per 1000 active leg ulcer cases.

2.2.2 A Norwegian paper from 1990 estimated a population of 6,000 patients from a population of 4,600,000, using the number of patients treated in a defined area. This equates to 1.3 per 1,000. A number of papers have reviewed the population and most identify incidence within a particular sub group e.g. those who have developed the condition as a result of a specific cancer treatment.

2.2.3 It must also be noted that certain areas of Wales have a higher than average elderly population. This then increases the incidence of lymphoedema further as it occurs in 8 per 1,000 in the over sixty-fives and 14 per 1,000 in the over seventy fives

2.3 Incidence and prevalence of lymphoedema by aetiology

2.3.1 On reviewing the evidence on how individual causes of lymphoedema contribute to the overall burden of the condition a constant theme throughout the literature is evident, in that lymphoedema is a very much underestimated and under diagnosed condition. The evidence, as would be expected, shows great variation in the type and quality of research methodology undertaken. In addition there are a number of
limitations including the varying methods for diagnosing, measuring and assessing lymphoedema.⁹

2.3.2 Lymphoedema is generally classified as being either primary or secondary. **Primary Lymphoedema** is due to either congenital abnormalities or absence of lymph tissue. Three types of primary lymphoedema are recognised –

- Congenital (occurring at birth)
- Praecox (between ages of 1 and 35 years)
- Tarda (over 35 years of age).

The most common primary lymphoedema syndromes are Turner’s syndrome, Milroy’s disease, Noonan’s syndrome and Klippel-Trenaunay syndrome.

The population prevalence of primary lymphoedema is difficult to ascertain. A number of papers provide estimates which vary considerably. Incidence of between 1 in 10,000 and 1 in 33,000 have been reported²²,²³ and 1.5 per 100,000 in the population under 20²⁴ as well as a suggestion that up to half of all cases of lymphoedema are primary in origin.²⁵ An epidemiological study²⁶ identified 2,743 patients from surgical units with lymphoedema, 36.8% of whom had primary lymphoedema.

Within the UK, local audits and service reviews also estimate between 8% and 28% of patients referred to lymphoedema services are identified as having a form of primary lymphoedema.²,²⁷,²⁸

2.3.3 **Secondary Lymphoedema** develops as a consequence of disruption or obstruction of the lymphatic pathways. The main causes of secondary lymphoedema are listed in Table 3.
Table 3: Classification of Causes of Secondary Lymphoedema

<table>
<thead>
<tr>
<th>Classification</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trauma and tissue damage</td>
<td>o Lymph node excision</td>
</tr>
<tr>
<td></td>
<td>o Radiotherapy</td>
</tr>
<tr>
<td></td>
<td>o Burns</td>
</tr>
<tr>
<td></td>
<td>o Varicose vein surgery/harvesting</td>
</tr>
<tr>
<td></td>
<td>o Large/circumferential wounds</td>
</tr>
<tr>
<td></td>
<td>o Scarring</td>
</tr>
<tr>
<td>Malignant Disease</td>
<td>o Lymph node metastases</td>
</tr>
<tr>
<td></td>
<td>o Infiltrative carcinoma</td>
</tr>
<tr>
<td></td>
<td>o Lymphoma</td>
</tr>
<tr>
<td></td>
<td>o Pressure from large tumours</td>
</tr>
<tr>
<td>Venous disease</td>
<td>o Chronic venous insufficiency</td>
</tr>
<tr>
<td></td>
<td>o Venous ulceration</td>
</tr>
<tr>
<td></td>
<td>o Post-thrombotic syndrome (DVT)</td>
</tr>
<tr>
<td></td>
<td>o Intravenous drug use</td>
</tr>
<tr>
<td>Infection</td>
<td>o Cellulitis/erysipelas</td>
</tr>
<tr>
<td></td>
<td>o Lymphadenitis</td>
</tr>
<tr>
<td></td>
<td>o Filariasis</td>
</tr>
<tr>
<td>Inflammation</td>
<td>o Rheumatoid arthritis</td>
</tr>
<tr>
<td></td>
<td>o Psoriatic arthritis</td>
</tr>
<tr>
<td></td>
<td>o Dermatitis/eczema</td>
</tr>
<tr>
<td></td>
<td>o Sarcoidosis</td>
</tr>
<tr>
<td>Immobility and Dependency</td>
<td>o Dependency oedema</td>
</tr>
<tr>
<td></td>
<td>o Obesity</td>
</tr>
<tr>
<td></td>
<td>o Paralysis</td>
</tr>
<tr>
<td>Artificial Lymphoedema</td>
<td>o Self harm</td>
</tr>
</tbody>
</table>

Adapted from: Lymphoedema Framework. Best practice for the management of lymphoedema, International consensus. London MEP Ltd, 2006.\textsuperscript{15}

**Trauma and tissue damage**
Most of the evidence relating to the incidence of lymphoedema after trauma is related to the surgical and/or radiotherapeutic treatment of melanomas, breast or genito-urinary carcinomas. In patients undergoing groin dissection significant rates of 40-55% have been reported.\textsuperscript{29,30} Scars\textsuperscript{31} and burns\textsuperscript{32} have also been linked to lymphoedema as causal factors.
2.3.4 Malignant disease

Breast cancer
The incidence of breast cancer related lymphoedema literature is perhaps the most complete and the topic of a number of reviews.\textsuperscript{17, 33-38} The development of lymphoedema as a consequence of breast cancer or its treatment has long since been recognised. The incidence ranges from 6\% to 42.4\% in patients who had been treated with a combination of surgery and radiation for breast cancer. The majority of opinion puts the incidence somewhere in the region of 12\%–25\%.\textsuperscript{35-41} However, a number of papers suggest evolving surgical techniques such as sentinel lymph node biopsy\textsuperscript{42,43} will ultimately reduce the incidence of lymphoedema in patients not requiring a full axillary clearance, however there is little information to substantiate a population reduction in lymphoedema at the present time.

Melanoma
Early studies place the incidence of melanoma related lymphoedema between 23\% and 80\%.\textsuperscript{26, 44-47} However, with advances in treatment options including sentinel lymph node biopsy without full groin dissection, the literature indicates a reduction in incidence,\textsuperscript{48-49} around the 20\% mark although there are no randomised controlled trials to validate these claims.

Sarcoma
The incidence following wide local excision and radiotherapy is in the range of 30\%-50\%.\textsuperscript{26}

Gynaecological cancers
There is a lack of reliable information on the incidence of gynaecological cancer related lymphoedema and is highlighted in recent reviews.\textsuperscript{26, 50} A study published in 2007 of 802 survivors\textsuperscript{51} identified 10\% with a diagnosis of lymphoedema and 15\% with symptomatic swelling. Another study in 2003 of 468 patients found an 18\% incidence.\textsuperscript{52} The most gynaecological lymphoedema was found to be present in carcinomas of the vulva with rates of up to 48\%.\textsuperscript{53-55} Information on cervical cancer is the most common with the incidence of lymphoedema in patients undergoing hysterectomy and radiotherapy varying from 11\%-50\%.\textsuperscript{56-59}

Genitourinary cancers
The incidence of genitourinary cancers is largely unknown and varies according to type and location of the tumour itself. Penile carcinomas range in a reported incidence from 100\% if treated with inguinal dissection to 16\%-28.5\% by inguinal lymphadenectomy.\textsuperscript{60-63} Bladder carcinoma treated by radical radiotherapy indicates a 20\% incidence of lymphoedema and if treated by radical cystoscopy 10\% incidence.\textsuperscript{26} There is limited evidence on the incidence of lymphoedema related to prostate cancers as the majority of patients presenting with swelling are palliative and are logged as such not prostate. The report of lymphoedema services review group in Northern Ireland estimated that 10\% of prostate cancer patients went on to develop lymphoedema.\textsuperscript{64}
2.3.5 Venous Disease
Impaired lymphatic function has been identified as a common symptom of venous disease including venous ulceration. A study in 2004 reviewing the prevalence of leg ulceration in a population of 252,000 identified 113 patients 0.45/1000. 42% of those patients also had lymphoedema.

A study of 689 leg ulcers in 555 patients, identified 17 patients for whom lymphoedema was the cause of their ulcer and an additional 11 patients for which the cause was a mix of lymphoedema and venous reflux (approx 4% related to lymphoedema). This study also identified a leg ulceration population prevalence of 1.5 per 1,000 over 65 years.

2.3.6 Infection/Cellulitis
Chronic lymphoedema is both a risk factor for and a result of erysipelas/cellulitis. Cellulitis is one the primary causes of infection-related lymphoedema. Whilst there is scant evidence on the incidence of cellulitis, a recent Cochrane review of the literature cited a study which identified a rate of 4 to 25 cases per 10,000 in the over 65 age group.

In a study of 176 patients admitted to hospital with cellulitis, lymphoedema was found to be a major risk factor and was present in 18% of cases. Another study suggests that cellulitis may be present in up to 50% of patients suffering from severe forms of lymphoedema as compared to 1/1,000 in the general population. One paper identifies cellulitis as a complication in 20-30% of lymphoedemas. However recurrent cellulitis can lead to lymphoedema which itself will produce more swelling and a predisposition to infection leading to a destructive cycle.

2.3.7 Inflammation
There is limited evidence on lymphoedema prevalence amongst patients suffering from inflammatory conditions. There have been papers that identify lymphoedema as a rare complication of dermatitis, and arthritis.

2.3.8 Immobility and Obesity
Although there is limited evidence on immobility, weight gain and increased body mass index have been considered by some as a risk factor in developing
lymphoedema. Obesity in particular is well documented as playing a causal role and is a poor prognostic factor in response to lymphoedema treatment.\textsuperscript{75-78}

2.4 How many people in Wales suffer with lymphoedema?

2.4.1 Based on the prevalence of lymphoedema found in the study\textsuperscript{17} of 1.33 per 1,000 there would be at least 4,000 lymphoedema sufferers in Wales. However, the prevalence rates for the last 5 years in the established clinics show an annual rise and the average in 2008 was 2 per 1,000 this would mean 6,000 patients in Wales. This does not include the undiagnosed and those not referred due to lack of services in Powys, Ceredigion and South East Wales. In Carmarthenshire the incidence in 2008-2009 is 3.25 per 1,000, in Swansea it is 3.5 per 1,000 and South East Wales it is 2.3 per 1,000 (Based only on their cancer figures). These figures are based on the number of lymphoedema cases in the data collected for 2008-2009. In Carmarthenshire and Swansea, the split between cancer patients and non cancer patients is 66%-34% and 62%-38% respectively. The Wrexham lymphoedema service, which is the longest established service, the ratio is 50%-50%. In the Foeldi Clinic in Hinterzarten Germany which was established in the 1980’s the proportion of cancers to non cancers is 33%-66% suggesting that the prevalence rate is set to continue.

![Prevalence Rates](image)

2.4.2 In reviewing the statistics from the Welsh Cancer Intelligence and Surveillance Unit (see Table 2.4.2) there would be up to 611 new breast cancer related lymphoedema patients, 99 melanoma patients, up to 522 gynaecology cancer patients, up to 32 penile carcinomas patients, 215 prostate cancer patients, 1-2 sarcoma patients and up to 195 bladder patients. In total there would be up to 1,676 new lymphoedema patients referred from a cancer origin annually in Wales. However the total number of patients living with lymphoedema in Wales will be related to the
survival rates for these cancers. As five year survival rates improve there will be implications for the requirements in lymphoedema services.

Table 2.4.2 Incidence Estimates of Lymphoedema secondary to cancer

<table>
<thead>
<tr>
<th>Doctoral</th>
<th>New cases per year</th>
<th>Incidence of lymphoedema</th>
<th>No Of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer</td>
<td>2444</td>
<td>12%-25%</td>
<td>293-611</td>
</tr>
<tr>
<td>Melanoma</td>
<td>497</td>
<td>20%</td>
<td>99</td>
</tr>
<tr>
<td>Gynaecology Ca</td>
<td>1043</td>
<td>15%-50%</td>
<td>157-522</td>
</tr>
<tr>
<td>Penile Ca</td>
<td>32</td>
<td>16%-100%</td>
<td>5-32</td>
</tr>
<tr>
<td>Prostate Ca</td>
<td>2146</td>
<td>Estimate 10%</td>
<td>215</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>3</td>
<td>30%-50%</td>
<td>1-2</td>
</tr>
<tr>
<td>Bladder Ca</td>
<td>977</td>
<td>10%-20%</td>
<td>98-195</td>
</tr>
</tbody>
</table>

In analysing the data from the 2004 paper where 0.45 per 1,000 of the population have leg ulcers then 13,229 patients will be diagnosed in Wales. If 42% of them had lymphoedema then there would be at least 5,500 sufferers from a venous disorder. This enhances the need for collaboration and joint working with tissue viability and dermatology departments.

Key Actions Required | By Who | By When (End of) |
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Appoint an all Wales Project Manager, for 2 years, to lead and champion the implementation of the Strategy</td>
<td>Local Health Boards working and funding collaboratively</td>
<td>March 2010</td>
</tr>
<tr>
<td>Plan, secure and deliver high quality lymphoedema services for assessment and management to meet the needs of both cancer and non cancer patients</td>
<td>Local Health Boards Velindre NHS Trust and Voluntary Sector</td>
<td>March 2011</td>
</tr>
<tr>
<td>Develop Evidence based lymphoedema care pathways and implement across all health care settings to manage lymphoedema and the obstacles to recovery</td>
<td>Developed by – Project Manager Implemented by - Local Health Boards, Velindre NHS Trust and Voluntary Sector</td>
<td>March 2011 March 2012</td>
</tr>
<tr>
<td>Review and standardise patient information leaflets on preventative strategies and self management</td>
<td>Developed by - Project Manager Implemented by - Local Health Boards</td>
<td>March 2011 March 2012</td>
</tr>
<tr>
<td>Implement education and training packages for all health care professionals to support better management of lymphoedema and reduce associated risks</td>
<td>Developed by - Project Manager Implemented by - Local Health Boards</td>
<td>March 2011 March 2012</td>
</tr>
</tbody>
</table>
Chapter 3  
Prevention and Reducing the Risk of Lymphoedema 

3.1 Background 

3.1.1 It is important that all patients whose treatment has predisposed them to developing lymphoedema are informed of the risk. Information should be provided on what to do if any signs and symptoms occur, enabling patients to be referred promptly to lymphoedema services and appropriate management initiated. 

3.2 Cancer groups 

3.2.1 As lymph node surgery and radiotherapy can cause lymphoedema in all cancers, in some areas strategies have been initiated, to improve patient information on the potential risk of lymphoedema. The most successful initiative has been in breast cancer patients. 

3.2.2 Breast- Since the introduction of the Sentinel Node Biopsy (SNB), unnecessary complete axillary lymph node clearance should have reduced. Therefore the risk of lymphoedema should in theory decrease, however only 60% of patients would be eligible for having SNB and radiotherapy can still cause lymphoedema. 

With such a high incidence of breast cancer related lymphoedema, rehabilitation and prevention of lymphoedema classes were initiated in certain areas of Wales. 

In Swansea all patients undergoing axillary surgery are invited to attend six, 2 hour sessions in a local leisure centre. This lymphoedema preventative programme has seen the incidence of breast cancer related lymphoedema reduce from 1 in 4 to 1 in 12 people. Patient satisfaction is extremely high with improved access and efficiency. 

In Wrexham, Carmarthenshire and Pembrokeshire all breast cancer patients are invited to a self help education session aimed at reducing the risk of lymphoedema. This has been based on the award winning Swansea scheme. 

In South East Wales Lymphoedema Service a 4 week breast cancer lymphoedema and rehabilitation program is provided.
All breast cancer patients should be pre assessed prior to their breast cancer surgery with measurements taken of their upper limb volume and shoulder mobility. This gives a starting baseline and changes can then be accurately recorded. Breast cancer patients must be given written information on the risk of lymphoedema and preventative strategies including skin care, exercise and prevention of infections. To reduce the occurrence of lymphoedema and improve function patients should also be followed up at 6 weeks and 1 year post operatively, following the award winning Abertawe Bro Morgannwg scheme.

General Practitioners should also be made aware that upper limb compression garments are now available on prescription and breast cancer patients at risk of lymphoedema may benefit from wearing a compression garment when they are travelling on an airplane.

3.2.3 Gynaecological cancers- The first Macmillan gynaecological cancer rehabilitation and prevention of lymphoedema and incontinence scheme started in October 2008 in the Abertawe Bro Morgannwg University NHS Trust. The scheme is following the same format as the award winning breast scheme.

3.2.4 Genitourinary, melanoma and head and neck cancers- Patients within these categories will benefit from lymphoedema prevention sessions and patient information which will need to be considered when developing local delivery plans.
3.3 The management of obesity

3.3.1 The prevention and management of obesity should be a priority for all, because of the considerable health benefits of maintaining a healthy weight and the health risks associated with it. A healthy active lifestyle is important in preventing certain conditions and maintains independent functional capabilities. It is also one of the key implementations for the Welsh Assembly Government and has been a key priority for implementation by NICE. Public health, chronic condition managers and health professionals in all primary care settings should ensure that preventing and managing obesity is a priority, at both strategic and delivery levels.

3.3.2 Many people with lymphoedema are obese and are unaware that their obesity has exacerbated their oedema and not the other way around. Many patients state that they thought exercise would aggravate their condition. Evidence suggests that exercise and muscle strengthening can have a positive impact on function by
- reducing pain and stiffness
- improving muscle strength and endurance
- maintaining cardiovascular fitness
- supporting weight reduction
- contributing to an improved sense of well being.

Obesity may also be a risk factor regarding lymphoedema development in breast cancer patients. Evidence has shown that patients are far more at risk of developing lymphoedema if they gain weight after their treatment.

3.3.3 The local situation in Wrexham has illustrated that the non cancer lymphoedema patients have a far higher body mass index than the cancer patients. 44% of non cancer lymphoedema patients compared to 6% of cancer lymphoedema patients have a BMI over 40 putting them into the obesity III classification. These grossly obese patients can be a manual handling risk to practitioners and are also an enormous burden on the resources of the clinic in terms of time and providing made to measure compression garments. However by treating their lymphoedema the incidence of infections will decrease and patients will begin to maintain their health and improve their activity level.

![Body Mass Index in Wrexham Lymphoedema Clinic](image-url)
3.4 Management of post thrombotic syndrome

3.4.1 Prevention of lymphoedema must also include the active management of post thrombotic syndrome, which can cause mild oedema to incapacitating swelling with pain and ulceration. Evidence has shown that up to 60% of patients develop this syndrome following an episode of deep vein thrombosis, but if they were issued with compression garments this reduces by 50%. Further collaboration is needed in this area. 86-87

3.5 Improvement in community nurse awareness

3.5.1 Improving lymphoedema knowledge in the community will ensure simple preventative measures are taken. Early recognition and referral will reduce the level of lymphoedema severity. Not only will this lessen the input of the specialist’s time but with better education will enable the district and practice nurses to collaborate on care in the community. 88-89

All front line staff including podiatrists, health visitors, practice nurses and GPs should be able to offer basic information to at risk patients including skin care and preventative information.

In Carmarthenshire, nominated practice nurses from each of the GP surgeries have attended a workshop on the management of lymphoedema. This one day course offered them practical support in the ongoing management of chronic oedema patients and the chance to collaborate with the lymphoedema clinic. Evaluation was extremely high with applicants stating ‘I feel confident that this training day has adequately prepared me to start treating chronic oedema patients effectively’…‘I have got over the feeling of inadequacy’…All district and practice nurses registered on the North Wales tissue viability courses receive lymphoedema training.

3.6 Early referral from orthopaedic services

3.6.1 Patients who are waiting for hip or knee surgery may develop lower limb dependency oedema as a result of immobility, due to pain and a reduction in the calf muscle pump activity. As the immobility increases the oedema can progress to such an extent that it could prevent surgery. Patients referred in a timely manner to lymphoedema services can maintain and enhance as much of their mobility as possible by decreasing the dependency. Education and close working patterns between the orthopaedic outpatients and the lymphoedema service will ensure that there are no delays in surgery due to oedema. Physiotherapists are the ideal front line professionals to offer simple advice such as skin care and activity.

3.7 The management of cellulitis

3.7.1 This disabling and painful condition occurs as both a precursor of lymphoedema and as a complication. It causes much distress which, with appropriate management
of lymphoedema and prompt response to early signs of infection or inflammation, can be avoided. Approximately 29% of lymphoedema patients develop cellulitis\(^3\).

3.7.2 Early recognition of cellulitis and timely treatment is paramount in the reduction of severity of existing lymphoedema. In a multivariate analysis of risk factors the presence of lymphoedema was extremely high with a factor of 71.2.\(^9\) Untreated cellulitis leads to tissue breakdown which damages the initial lymphatics and increases the risk of further cellulitis attacks \(^9\).

29% of chronic oedema patients had experienced at least 1 episode of cellulitis and 27% of this group had at least 1 hospital admission for acute management with I.V antibiotics.\(^3\)

3.7.3 In an audit of lymphoedema patients experiencing Cellulitis in Abertawe Bro Morgannwg Trust, 41% developed this complication prior to treatment, whilst only 9% occurred afterwards. Of 21 patients experiencing 3 or more bouts of cellulitis only 2 did so subsequent to treatment.

A patient case example in Wrexham involved hospital admission for 30 days at a cost of £7,200, followed by 112 district nursing visits and £1500 worth of dressings. Subsequent lymphoedema specialist management over 23 clinic attendances cost £1300 that included dressings.

There would appear to be large cost savings, both personally and financially to the patient and the NHS through effective management of both cellulitis and lymphoedema \(^9\).

3.7.4 Patients who experience repeated episodes of cellulitis i.e. 2 or more attacks per year should be prescribed with prophylactic oral antibiotics. After two years of successful prophylaxis the antibiotics may be discontinued. However if the cellulitis reoccurs life long prophylaxis is necessary.\(^15\)

Presently we know that patients can be treated in an unplanned way and chronic conditions account for 80% of GP consultations. A simple measure like prescribing prophylactic antibiotics if necessary could prevent admissions and more chronic disease. The management of cellulitis in patients with lymphoedema should follow the British Lymphology Society antibiotic guidelines.\(^15\) The UK Dermatology Clinical trials network is in the final stages of a study, how to manage recurrent limb cellulitis, information is available from [http://www.ukdctn.org/ongoing/patch/](http://www.ukdctn.org/ongoing/patch/).

3.7.5 Patients who experience cellulitis, with no previous diagnosis of lymphoedema, should be assessed for swelling and referred to the lymphoedema services promptly if lymphoedema is diagnosed. Correct management of oedema can reduce the episodes of cellulitis considerably.

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3.8 Conclusion

3.8.1 Lymphoedema prevention is not difficult, it is mainly about giving those at risk appropriate information and advice on what they should do and what to avoid. In Wales only pockets of preventative strategies have been developed and this needs to be addressed.

<table>
<thead>
<tr>
<th>Key Action Required</th>
<th>By Whom</th>
<th>By When (end of)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop evidence based cellulitis care pathways and implement use across all health care settings</td>
<td>Developed by – Project Manager, WALS Implemented by - Local Health Boards, Velindre NHS Trust and Voluntary Sector</td>
<td>March 2011</td>
</tr>
<tr>
<td></td>
<td></td>
<td>March 2012</td>
</tr>
<tr>
<td>All breast cancer patients must have access to lymphoedema prevention and education schemes to reduce their risk of developing lymphoedema.</td>
<td>Implemented by – Local Health Boards</td>
<td>March 2011</td>
</tr>
<tr>
<td>All lymphoedema services in conjunction with physiotherapy and dietetics must offer an active management programme for obese patients.</td>
<td>Implemented by – Local Health Boards</td>
<td>March 2012</td>
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</tbody>
</table>
Chapter 4
Diagnosis and Assessment of Lymphoedema

**Aim:** To ensure a timely and appropriate assessment and diagnosis of lymphoedema to minimise physical, psychological and economic impact.

### 4.1 Diagnosis

4.1.1 Lymphoedema is an incurable chronic condition, which progresses if left untreated. Early diagnosis will ensure that patients receive appropriate assessment and management. Lymphoedema treatment is effective at any stage of the condition but the earlier a patient is diagnosed may decrease the amount of treatment required. Improving health care professionals’ ability to recognise and diagnose lymphoedema is essential.

4.1.2 Lymphoedema is defined as an accumulation of fluid including proteins and other elements in the tissue spaces due to an imbalance between interstitial fluid production and transport. It arises from congenital malformation of the lymphatic system or from damage to the lymphatic vessels and/or lymph nodes. Lymphoedema can be associated with pain, discomfort, heaviness, functional limitations including decreased mobility and muscle strength, disfigurement, psychological distress and an elevated risk of recurrent cellulitis.

4.1.3 Differential diagnosis of lymphoedema occurs in:

- **Lipoedema** - which is a bilateral symmetrical fatty swelling that occurs in the lower limbs from an excessive adipose fat deposition.
- **Lipolymphoedema** - occurs when a patient originally has lipoedema but through obesity, immobility, chronic venous insufficiency or skin deterioration progresses into lymphoedema.
- **Chronic Lymphovenous Oedema** - chronic overloading of the lymphatic system regularly occurs due to impaired venous return in the lower limbs. Initially the lymphatic system will attempt to compensate for the venous system and increase its capacity but eventually the lymphatic system will fail causing lymphovenous oedema. This frequently goes unrecognised and leads to chronic swelling, leaking lymphorrhoea, skin breakdown and ulceration, which are seen daily in primary care.

4.1.4 A thorough assessment with detailed clinical history, examination and limb measurements are the key stones to establishing a diagnosis. If a lymphoedema diagnosis is uncertain radiological investigations such as lymphoscintigraphy may be necessary to establish a diagnosis. Dermatology and Vascular input is also important in multi pathology complex patients and collaboration is recommended. An accurate diagnosis of lymphoedema is essential and it is important that patients referred to the service have had other causes of oedema excluded i.e. arterial problems, cardiac failure or malignancy.
4.2 Assessment of lymphoedema

An accurate assessment is essential in order to effectively treat patients with lymphoedema; a holistic approach must be adopted. Prior to referral to the lymphoedema service the referring GP or consultant should have performed a medical assessment or initial screening investigations, to exclude other medical reasons for swelling such as a history of cardiac failure, DVT, renal or arterial problems.

Lymphoedema patients at risk of arterial vascular disease should be referred to vascular services for assessment if there are concerns about applying compression. Lymphoedema clinics should have access and be competent in using ankle brachial pressure index (ABPI) using Doppler probes. Although it is acknowledged that ABPI readings may be difficult to determine in a grossly swollen limb, the use of the toe brachial pressure index (TBPI) should then be used. International consensus recommends that a multi modal assessment includes:

4.2.1 Medical assessment
- History of lymphoedema including onset, duration, exacerbation
- Cancer history and treatment
- Family history
- Previous oedema treatment
- History of cellulitis with number of attacks per year and if prophylactic antibiotics have been prescribed
- Pain, duration, sensation, visual analogue scales
- Past Medical History
- Drug History
- Allergies
- Social information including mobility, hobbies, occupation, and sleeping history e.g. in bed or chair
- Weight and Body Mass Index

4.2.2 Physical examination
- Skin and tissue changes including:
  - Hyperkeratosis (thickened brown pigmentation)
  - Skin colour (e.g. erythema; brownish pigmentation)
  - Skin temperature
  - Lymphangioma (Lymph blisters)
  - Papillomatosis (warty growths on the skin due to fibrosis)
  - Fungal infections
  - Lymphorrhea (leakage of lymph fluid through the skin surface)
  - Pitting or non-pitting oedema
  - Skin texture (soft, hardened, shiny, taut, fibrosis, ulceration);
  - Skin folds
- Range of movement, mobility, muscle strength and functional ability
- Neurological deficits
- Vascular assessment including arterial vascular status prior to applying compression if relevant
- Measurement of limb volume by
- Circumference volumetric measurements every 4cm using a tape measure
- Perometry

4.2.3 Psychological assessment
A diagnosis of lymphoedema, its association with cancer and being incurable can lead to significant psychosocial effects. Anxiety, depression, body image problems, reduced self esteem and motivation can be observed. The lymphoedema assessment should include sufficient information that a referral to psychological or social support can be made.

4.2.4 What method should be used to calculate limb volume in Wales?
Calculation of volume from circumferential measurements is the most widely used method of calculating limb volume. Measurements are calculated from fixed anatomical points along the limb and repeated every 4 cm. Circumferential measurements of limbs are put into a specialist calculator or computer programme for calculation of limb volume, which can be used to aid diagnosis and monitor effect of treatment. The method used to calculate limb volume should be easy to use, accessible, non-invasive and inexpensive. Therefore this will be adapted as the method used in Wales although ongoing training is required to ensure reliability.

4.3 Early recognition and referral criteria

4.3.1 A diagnosis of lymphoedema is given if there is a 5% difference in limb volume circumference measurements. Good practice recommends that patients have limbs measured prior to surgery or radiotherapy if the lymph nodes are to be affected. Changes from the base line can be recorded and are more accurate in detecting a change in fluid volume. Patients who develop a 5% difference must be referred to a lymphoedema service, assuming that there is no known cause for the difference in volume.

4.3.2 Patients who are known to be at risk of developing lymphoedema must be informed of this potential risk and be referred to a lymphoedema service for assessment if they complain of swelling or heaviness in the limb, as well as difficulty in getting shoes or jewellery to fit.

4.3.3 The earlier a lymphoedema patient is referred, the less severe the swelling is and consequently decreases the amount of treatment required. Education and training on identifying lymphoedema is paramount in primary and secondary care.

4.3.4 Patients referred to a lymphoedema service need to be categorized as routine, urgent or palliative. Routine patients need to be assessed within 14 weeks of referral, (based on current therapy targets), urgent within 4 weeks and palliative within 5 working days. Chart 1 gives information on whether a patient is routine, urgent or palliative.
Pathway: Referral to a lymphoedema service

Does your patient have lymphoedema or chronic oedema?

YES  NO

Lymphoedema referral not indicated at present. Provide preventative advice to patient including:
- Skin care (including moisturising daily)
- Exercise (improving mobility)
- Maintenance of a healthy body weight

Does your patient have advanced disease?

YES  NO

- Has the patient had numerous episodes of cellulitis in the affected area?
- Leaking fluid?
- Truncal/ breast swelling?
- Head or neck swelling?
- Genital Oedema?
- Severe hand swelling?

Tick Palliative box on lymphoedema referral form  Will be seen within 5 days

YES  NO

Tick Urgent on the referral form  Will be seen within 3 - 4 weeks

Tick Routine on lymphoedema referral form  Will be seen within 6 -14 weeks
<table>
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<th><strong>Key Action Required</strong></th>
<th><strong>By Whom</strong></th>
<th><strong>By When</strong></th>
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</table>
| Develop all Wales assessment tools and referral forms for implementation and use across all lymphoedema services in Wales | **Developed by** – Project Manager  
**Implemented by** – Local Health Boards, Velindre NHS Trust, GPs and Voluntary Sector | March 2011  
March 2012 |
| Develop and implement lymphoedema referral protocols and criteria supported by appropriate training across all health care settings to aid early assessment and diagnosis of lymphoedema | **Developed by** – Project Manager  
**Implemented by** – Local Health Boards, Velindre NHS Trust, GPs and Voluntary Sector | March 2011  
March 2012 |
| Undertake an evaluation of current services to identify good practice to be disseminated to all areas across Wales to aid service improvements | Project Manager | March 2011 |
Chapter 5
Management of Lymphoedema

5.1 Background

5.1.1 The main aim is to certify that patients can see the right professional, in the right place at the right time and receive evidence based management across all levels of the Chronic Conditions Management Model i.e. from prevention to chronic elephantatic lymphoedema.

5.1.2 Not all individuals will require specialist lymphoedema services, therefore the care should be provided across all 4 levels of the Chronic Conditions Management Module. Further lymphoedema awareness and education must be achieved in all primary care staff to improve lymphoedema management skills. Untreated long standing lymphoedema can lead to functional impairment, reduced self esteem and psychological problems. Appropriate evaluation of the psychological health of the patient needs to be undertaken and referral to appropriate service instigated.

5.1.3 All patients with a lymphoedema diagnosis must have access to effective and efficient management of the condition with the aims of treatment management being:
- Restore maximum functional independence;
- Reduce risk of infection;
- Provide long-term control of limb swelling;
- Improve limb shape;
- Maximise lymph drainage in affected areas and minimise fibrosis;
- Provide psychological support;
- Educate patients in understanding their condition and rationale for treatment;
- Promote self care and independence;

5.1.4 Lymphoedema management tends to be divided into intensive (Decongestive) and maintenance treatment. Intensive treatment is specialist led and normally consists of the patient attending daily or every other day for 2/3 weeks. Each session the limb is washed, massaged, moisterised and multilayer lymphoedema bandaged. Intensive treatment is indicated when the oedematous limb is
- Over 20% difference in swelling compared to the unaffected side
- There is a distal to proximal distorted limb shape
- There are skin folds, damaged or ulcerated skin
- Fibrosis or hardening of the tissues
- Lymphorrhoea
- Limb is too large to fit off the shelf compression garments although made to measure garments could be provided prior to treatment
- Swelling is evident in the head, neck, trunk, breast or genitalia

In cases where the patient is already being seen by community nurses, the intensive treatment can be modified and the multilayer lymphoedema bandaging can be shared with the community staff. Collaboration or shared care can increase community nurses skills and fits well with the Chronic Conditions Model.
After intensive treatment patients are seen monthly, bimonthly and then every 4 months - working on a sliding scale dependent on their progress. The second phase of treatment, maintenance, transfers the management back to the patients rather than the specialist. They then must be reassessed at 4-6 monthly intervals at the lymphoedema service for the re-issuing of specialist compression garments and assessment.

<table>
<thead>
<tr>
<th>Intensive Phase</th>
<th>Maintenance Phase</th>
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<tbody>
<tr>
<td>Manual lymphatic drainage (MLD)</td>
<td>Compression garments</td>
</tr>
<tr>
<td>Multilayer lymphoedema bandaging (MLLB)</td>
<td>Skin care</td>
</tr>
<tr>
<td>Skin care</td>
<td>Exercise</td>
</tr>
<tr>
<td>Exercise</td>
<td>Simple Lymph drainage or MLD if appropriate</td>
</tr>
<tr>
<td></td>
<td>MLLB if appropriate</td>
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</table>

Lymphoedema is rapidly changeable. Maintenance patients often need intensive treatments to help them manage their swelling. Infections, hot weather, cuts, immobility can sometimes lead to an exacerbation. Complex and palliative patients might also need ‘top up’ treatments including MLD and MLLB mainly due to the extent of their lymphoedema and other associated skin problems.

5.2 The Organisation of care

5.2.1 The Model and Framework for Chronic Conditions Management must underpin the organisation of care for lymphoedema. This will ensure the delivery of consistent management of all types of patients starting at health promotion. Patients attending other mainline services should be advised on the importance of skin care, exercise and a healthy diet. If lymphoedema is suspected then patients can be managed appropriately and referred on the specialist lymphoedema service in a timely fashion.
Patients whose lymphoedema is controlled and less than 10% can be managed by link workers in the community or by dedicated lymphoedema health care support workers. This ultimately will free up specialist time. Dedicated link workers in the community must have completed the lymphoedema education and have protected time to work with the clinic on a weekly or monthly basis to maintain their skills.

5.2.2 Integrating services more effectively is fundamental to the future of health and social care in Wales. The Community Services Framework provides key approaches which can ensure that services are accessible, effective and meet value for money goals.

- Improved co-ordination and collaboration of services enables lymphoedema services, primary care clusters, GPs and social services to work as a team within a defined area. E.g. shared care of lymphoedema patients undergoing intensive treatment and having social services input in the long term care of applying compression garments.
- Using shared service locations such as clusters of GP surgeries, community hospitals for joint clinics with the primary care team will enhance the knowledge
of the primary care staff and share the care. Joint assessment and collaboration with the tissue viability teams and dermatology is vital.

5.2.3 The Welsh Association of Lymphoedema Services (WALS) will develop a range of patient and health professional information, protocols and guidelines to assist the primary care teams in their decision making, when assessing the suitability of the need for referral to specialist lymphoedema service. Certain groups of patients cannot be managed by the primary care teams see table below.

<table>
<thead>
<tr>
<th>Special Groups</th>
<th>Factors Complicating Management</th>
<th>Management of Difficulties</th>
</tr>
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<tbody>
<tr>
<td>o Swelling of unknown origin</td>
<td>o Concomitant arterial disease</td>
<td>o Compression garment fitting problems</td>
</tr>
<tr>
<td>o Midline lymphoedema (head, neck, trunk, breast, genitalia)</td>
<td>o Concomitant diabetes mellitus</td>
<td>o Failure to respond after 3 months of standard treatment</td>
</tr>
<tr>
<td>o Children with chronic oedema</td>
<td>o Concomitant venous insufficiency with ulceration</td>
<td>o Wound that deteriorates or is unresponsive after 3 months treatment</td>
</tr>
<tr>
<td>o Primary lymphoedema</td>
<td>o Long term complications due to surgery or radiotherapy</td>
<td>o Recurrent cellulitis</td>
</tr>
<tr>
<td>o Family members with lymphoedema</td>
<td>o Severe Papillomatosis, hyperkeratosis or other skin conditions</td>
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</tr>
<tr>
<td></td>
<td>o Severe foot distortion/ bulbous toes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Sudden increase in pain or swelling in lymphoedematous site</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Chylous reflux</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Neuropathy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o Functional, social or psychological issues</td>
<td></td>
</tr>
<tr>
<td></td>
<td>o obesity</td>
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</table>

Adapted from the lymphoedema framework, Best practice for the management of lymphoedema International consensus. London MEP ltd 2006
5.2.4 Older people, those with end of life needs, or cognitive impairment and mental health problems will need special support in the planning of their care. This may include individual communication with the community psychiatric services to organise joint visits or the palliative care teams. Co-operation with carers and social services for access to specialist clinics at convenient times, with transport organised for those with disabilities as outlined in the Disability Discrimination Act. Lymphoedema link workers in palliative care can significantly improve palliative patients’ quality of life, if for example they have leaking limbs and were waiting for a lymphoedema specialist to assess.

5.3 Integrating primary and secondary care services

5.3.1 Although traditionally health care intervention begins with the primary care team; the lack of diagnostic and management skills in the community has led to lymphoedema services being instigated in secondary services. Lymphoedema is a relatively new specialty with the first service in Wales being set up in 1995. Due to the lack of provision of care many people presenting with lymphoedema fit into the complicated category and need specialist intervention. This is especially true of those with non-cancer related lymphoedema/chronic oedema. With increasing awareness in primary care, and better links with chronic disease management teams, referrals into lymphoedema services will continue to increase. However preventative strategies are effective and the incidence of breast cancer related lymphoedema should decrease.

5.3.2 The Wrexham lymphoedema service was set up in 1995. For the first 11 years activity increased at a steady pace. However in the last 2 years the service is finally levelling out. If all the services in Wales were properly resourced and accepted all lymphoedema referrals, it would take a considerable amount of time for the activity to plateau.
5.3.3 Lymphoedema services can be provided in a variety of different ways:

- **Specialist lymphoedema clinic**
  This facility must be staffed by qualified lymphoedema specialists, assisted by lymphoedema assistants or health care support workers with an appropriate NVQ level 2/3 qualification and administration skills. It must have close links with the Oncology, Dermatology, Vascular and Tissue Viability Multi Disciplinary Teams and referral criteria agreed for medical input and psychological support services. The equipment must be suitable for treating the morbidly obese or bariatric patients and all staff have specific manual handling skills.

- **Breast care nurse specialists**
  Breast care nurses often give advice to their breast cancer patients on the signs and symptoms of lymphoedema. In certain areas in Wales the breast care nurses have undergone specific lymphoedema training and are able to offer treatment for patients with moderate lymphoedema. In other areas the breast cancer nurses refer all their lymphoedema patients to the specialist service. Where access to lymphoedema services is unavailable breast care nurses are giving up an unacceptable amount of their time treating lymphoedema patients, sometimes at a cost to other vital aspects of their work caring for breast cancer patients. Breast care nurses should include and facilitate lymphoedema prevention programmes as an integral part of their role.

- **Community/leg ulcer/tissue viability clinics**
  An assessment of community nurses level of knowledge of lymphoedema has shown the majority admitting to adequate to poor understanding, which demonstrates an urgent need for ongoing education and support. The lymphoedema specialist can collaborate on patients who have both a vascular and lymphatic component to their swelling and are able to advise on different lymphoedema bandaging techniques plus specialist compression garment provision. Community nurses may not have a background in lymphoedema but with support and education, existing skills can be transferable to lymphoedema.

- **Prevention initiatives in residential and nursing homes for the elderly and sedentary patients.**
  This initiative would fit in with the aims of the Locality Network Teams for chronic conditions and with continued support and education from the lymphoedema team to reduce the incidence of lymphovenous oedema in the elderly and immobile patient.

5.3.4 The management of complex lymphoedema will require specialist input, this includes;

**Upper limb oedema:**
- All patients complaining of heaviness, reduced mobility with a history of breast cancer should be referred. Limb volume measurements are necessary and specialist software is not available to the community teams.
- All those with hand swelling
- With swelling of the trunk or breast
- History of recurrent cellulitis.
Those patients who have had bilateral breast surgery and need to have both arms monitored.

**Lower limb oedema:**
- Unilateral leg swelling cause:
  - Those who have skin folds, and severe skin changes including leaking lymphorrhoea
  - Those who are unable to wear proper foot wear due to foot swelling
  - The morbidly obese with recognised signs of lymphatic changes – Positive Stemmers sign, skin folds, and skin changes - patients would need to be placed on an obesity care pathway.
- History of recurrent cellulitis.

5.3.5 The interventions needed to treat this group of patients must be provided by the lymphoedema team. The clinical decision making changes daily as the swollen limb is treated and the therapist depends on clinical expertise to address the changes in limb shape. A district or practice nurse will not have the volume of patients to gain the experience and will have difficulties in applying different foams and paddings. Shared care can be undertaken in collaboration on a named patient basis. Following appropriate education and training, a Lymphoedema Link Nurse Scheme, within each community health care team, must be developed to facilitate collaboration.

5.3.6 Other treatments available to lymphoedema patients include intermittent pneumatic compression and surgery. Intermittence compression is a mechanical pump that inflates a multi-chambered plastic sleeve worn over the limb to specific pressures in timed cyclical pulsations. There is considerable debate over its effectiveness. Surgery is not usually indicated unless treating extensive scrotal or genital oedema. Liposuction is also a relatively new technique that has become available in Europe and more recently in Scotland. Patients still have to wear their compression garments daily only removing them for bathing.
5.3.7 The model of care for the management of lymphoedema will depend on local and regional planning and delivery decisions. In the short term, investment is required so that all areas in Wales have lymphoedema services with adequate staffing levels.

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<tr>
<th>Key Action Required</th>
<th>By Whom</th>
<th>By When (end of)</th>
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<tbody>
<tr>
<td>Assess and review the ongoing needs of lymphoedema patients in conjunction with chronic condition management</td>
<td>Local Health Boards</td>
<td>March 2011</td>
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<tr>
<td>Establish community lymphoedema sessions for lesser complex patients to be delivered in community hospitals /GP surgeries</td>
<td>Local Health Boards Primary Care</td>
<td>March 2012</td>
</tr>
<tr>
<td>Establish a Lymphoedema Link Nurse Scheme, within each community health care team, to facilitate collaboration.</td>
<td>Local Health Boards</td>
<td>March 2011</td>
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</tbody>
</table>
Chapter 6
Facilitating and Managing Independence

6.1 Background

6.1.1 Maximising independence is a key priority for chronic condition management and community services, in partnership with voluntary sector organisations for people with lymphoedema. All treatment approaches must support self-management, building on the patient and carer’s developing lymphoedema knowledge. Simple strategies such as daily moisturising of their affected limb and basic exercises should be encouraged.

6.1.2 All patients attending a lymphoedema service will be supported to maintain their lymphoedema improvements. If patients are unable to don and doff their compression garments then social care services must be involved. If patients wear their garments daily then their lymphoedema will remain under control reducing hospital admissions for cellulitis. All lymphoedema services will provide patients with knowledge and information to enable them to be as independent as possible.

6.1.3 The Welsh Assembly Government has adopted the Social Model of Disability as the basis for all of its work on disability. The lymphoedema planning and delivery groups should be aware that people with lymphoedema can suffer with many symptoms including fatigue and pain on a daily basis. This makes mobility and normal activities of daily living difficult. Therefore lymphoedema should be recognised as criteria for the Welsh Assembly Government Access to Patient Transport.

6.2 Improving quality of life

6.2.1 Lymphoedema is incurable, but with specialist lymphoedema services in place significant improvements can be made to enhance quality of life and maximise independence by ensuring:
- Flexible, accessible, seamless multi-disciplinary services
- Education of the user and carer in lymphoedema management
- Support for behavioural and cognitive changes in accepting a non-curable chronic condition e.g. The Expert Patient Programme.
- Help in returning to work by giving employers information on limitations and helpful working conditions.
- Encouraging a healthy lifestyle

6.3 Access to information/signposting

6.3.1 Lymphoedema awareness is improving, often associated with other conditions e.g. cancer, skin disorders and obesity. Lymphoedema patients have frequently lived with the condition for many years after being told that “there is nothing to be done”. This leads to a great deal of uncertainty and anxiety regarding their future.
Primary lymphoedema patients are always relegated to second class citizens in comparison to cancer patients who have lymphoedema as a result of the cancer treatment.

We are isolated...we can speak from first hand experience of how we fight to maintain our independence. We do not want to be a burden on the state, unfortunately without NHS intensive and maintenance lymphoedema treatment that is exactly what we will become. Without treatment the lymphoedema ultimately prevents many of us from looking after ourselves and so we become a weight on the social care system’ Primary lymphoedema patient August 2009

6.3.2 Giving patients information will help them understand their condition and realise that there are others suffering with the same problems. The Lymphoedema Support Network (LSN) is a national charity founded in 1991, whose main aim is to ensure that every lymphoedema patient receives a correct diagnosis and suitable level of care. Another of its objectives is to promote a network of support groups throughout the UK for people with lymphoedema.

The LSN offers its members:
- Telephone information and support line
- Quarterly newsletters
- Current information on lymphoedema research and treatment
- Fact Sheets
- Web site
- Self help videos

Information on LSN can be accessed on www.lymphoedema.org/lsn/

Healthcare professionals and other agencies need to be aware of the patient information available from LSN, plus awareness and accessibility of their local lymphoedema service.

6.3.3 The British Lymphology Society (BLS) is a charitable organisation with a membership of health care professionals from various specialties who have a direct interest in promoting effective lymphoedema management. This group of professionals alongside the LSN have been instrumental in producing a consensus document on the management of cellulitis, which is available on line for clinicians.

Information on BLS can be accessed on www.thebls.com/

The main aims of the BLS include:
- Promote awareness about lymphoedema to the public, health care professionals and relevant health departments. This will include awareness about patients who are ‘at risk’, and those with chronic oedema with lymphatic deficiency.
- Re-evaluate current lymphoedema guidelines, and publish evidence-based standards that underpin treatment for the long term management of lymphoedema.
- Be actively involved in promoting the need for equitable and sustainable services for people living with lymphoedema.
- Ensure that the patient’s perspective is reflected in issues related to service development and delivery of care within the UK.
- Encourage participation in research, using validated methodology, to advance and improve outcomes for patients with lymphoedema.
Raise awareness about minimum standards, as defined by BLS, and endeavour to ensure that any person with lymphoedema should have access to a service that provides minimum standards.

6.4 Self management

6.4.1 Supporting people to self manage reduces their reliance on health and social care. To be effective during the earlier stages of assessment and management a contract (written or verbal) should be drawn up between the individual and the therapist. Patients need to be made aware that lymphoedema is chronic and effective management will only be achieved with their input, supported by the professionals.

6.4.2 Group sessions or a lymphoedema support group are a useful way in getting patients to share their lymphoedema experiences and help new sufferers. This is also a way of reducing isolation especially for those with body image problems and a lack of self esteem. Peer supporters reported a greater benefit in quality of life than those they helped. Their confidence increased and their perception of their selves changed.

6.4.3 A dynamic lymphoedema support group can get involved in activities such as organising fitness programmes for patients e.g. Tai Chi and Aqua aerobics. Support Groups are eligible to apply for funding from organisations such as local branches of Wales Council for Voluntary Action (WCVA), Sports Council for Wales and Health Challenge Wales.

The Wrexham Lymphoedema Support Group is an example of a patient group rising to the challenge by using its skills to promote healthy living for their peers and approaching local organisations for help. In 2008 the Group received a grant from

- Sports Council of Wales for £1,000 towards the cost of aqua aerobics at the local pool
- £1,000 from Health Challenge Wales/Wrexham for a Healthy Living and weight loss programme.
- £10,000 from the Association of Voluntary Organisations Wrexham towards equipment for the lymphoedema Clinic

6.5 Public and patient involvement

6.5.1. Involving service users is crucial to developing services that meet patients’ needs. People with lymphoedema should be fully engaged in contributing to service design, location and implementation of the service. When Local Health Boards plan and deliver new services in conjunction with the lymphoedema planning and delivery groups, it is vital that people with lymphoedema are fully consulted.

6.6 Personal assistance and social care

6.6.1 Lymphoedema patients who need personal assistance should have responsive and flexible services. This is particularly relevant for people who have undergone a
course of intensive lymphoedema treatment and are fitted with compression garments, which need to be applied and removed daily. The continuing management of chronic lymphoedema is only successful if the compression garments are applied correctly every day. Courses of treatment should not commence until agreement has been reached on who is going to apply the compression garments e.g. patient, carer or a social services care package.

6.7 Informal carers

6.7.1 Many people living with lymphoedema are supported by informal carers. Those with severe lymphoedema resulting in very large oedematous limbs, frequently suffering with cellulitis can suffer feelings of helplessness, irritation and anger, which can be directed at their family or carers.

Informal carers can suffer with fatigue and injury; this is especially true of carers who are at risk of manual handling injuries in caring for the morbidly obese lymphoedema patients. It is essential that unpaid carers have access to support and information if their contribution to the care is to be maximised.

6.8 Social inclusion

6.8.1 In a study of 823 lymphoedema patients, 80% had time off work and 9% gave up work because of the condition. Retention in work and back to work programmes are important in securing future employment for people with lymphoedema. Work conditions (standing or sitting still for long periods) can exacerbate lymphoedema and advice to employers on types of work and duration of certain activities can lessen the difficulties for the individual. The Department of Work and Pensions has produced a green paper A New Deal for welfare: Empowering People to Work. This document proposes a new gateway to benefits for people with illness and includes the provision of in work support to ensure people continue working.

<table>
<thead>
<tr>
<th>Key Action Required</th>
<th>By Whom</th>
<th>By When (end of)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual patient care plans must include a category for:</td>
<td>Local Health</td>
<td>March 2011</td>
</tr>
<tr>
<td>y self management</td>
<td>Boards</td>
<td></td>
</tr>
<tr>
<td>y access to weight reduction programmes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>y signposting patients to Expert Patient Programmes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review appropriate information and support groups available for all lymphoedema/chronic oedema enabling patient signposting</td>
<td>Local Health</td>
<td>March 2011</td>
</tr>
<tr>
<td></td>
<td>Boards</td>
<td></td>
</tr>
<tr>
<td>Ensure unpaid carers are actively involved in joint care planning for both care of the patient and their safety to prevent stress or injury to themselves</td>
<td>Local Health</td>
<td>March 2011</td>
</tr>
<tr>
<td></td>
<td>Boards</td>
<td></td>
</tr>
</tbody>
</table>
Chapter 7
Education, Audit and Research

7.1 Education and professional development

7.1.1 The British Lymphology Society’s Framework for Education (2001) outlines the skills needed for management of the different stages of lymphoedema.

Education should be delivered on three levels:

1. **All health care professionals** should be able to identify those at risk of developing lymphoedema and offer preventative advice including promoting good skin care and encouraging patients to be more active. HCP should ensure they have a general awareness of lymphoedema and to refer to lymphoedema services where necessary. All lymphoedema services should be providing a rolling programme of lymphoedema awareness that can be accessed by all primary and secondary staff. Programmes can range from an hour introductory in-service delivered in the work place e.g. physiotherapy departments or protected learning times for practice nurses to tailor made, one day packages for tissue viability or district nurses. This provision must be incorporated into the education remit of a lymphoedema specialist’s job specification.

2. **Link workers** must be developed with the appropriate education to ensure that all primary care teams have a staff member who is competent in the management of mild to moderate lymphoedema. These link workers will collaborate in shared care protocols in multilayer lymphoedema bandaging. They can also be trained in palliative care, nursing homes and elderly care wards. Training must be available in each of the Local Health Boards and could be linked to established education providers.

3. **All lymphoedema specialists** must have access to continuing education. They must attend a specialist course at degree/masters level from one of the recognised schools of lymphoedema management and ensure that their clinical competencies are updated regularly.

7.1.2 It has been reported that the level of lymphoedema and cellulitis knowledge differs greatly amongst GPs. Certain GPs have built up an excellent level of understanding of the condition and work closely with lymphoedema services. To ensure that this knowledge base is widespread it is important that lymphoedema and chronic oedema become a part of the GP’s protected learning education time. This must be arranged with the Local Health Boards. Cellulitis pathways and protocols must be developed in primary and secondary care. Prompt and appropriate cellulitis management will ultimately reduce unnecessary hospital admissions.

7.1.3 A Link-worker education study programme is available at the Abertawe Bro Morgannwg University Local Health Board and is in the planning stages in North
Wales. All lymphoedema link workers will need to be competent in assessment and multi layer bandaging and have their competencies monitored.

7.1.4 Lymphoedema specialists will need to have achieved a qualification in lymphoedema management or be willing to undertake a course of study. The lymphoedema management course will also include a qualification in Manual Lymphatic Drainage. Specialist Lymphoedema managements courses are available in Abertawe Bro Morgannwg University Local Health Board on an annual basis.

7.2 Competencies and skills

7.2.1 The Agenda for Change competency based framework defines the knowledge and skills required at various levels of working across the NHS. Competencies and skills amongst lymphoedema services need to be developed and standardised to ensure that link worker staff and collaborators maintain up to date skills.

7.2.2 Lymphoedema specialists need to update their clinical competencies every two years following a formal qualification in one of the recognised training schools. This should include:
   o Skills to treat complicated lymphoedema
   o Carry an active caseload
   o Provide education
   o Liaise with other specialties
   o Review critical incidents
   o Partake in audit of their service

7.3 Audit

7.3.1 Improving the knowledge base for lymphoedema within Wales is vital to facilitate the collection of more accurate information to strengthen service development. Audit must be the key tool in monitoring the planned improvement in lymphoedema services. The audit trail should follow the patient from referral through to the maintenance phase of lymphoedema management. Services must be audited against the standards and key actions set out in this document including the International Lymphoedema Framework Project, British Lymphology Society and Welsh Association of Lymphoedema Services.

7.3.2 The development of a lymphoedema audit programme for all of Wales must fulfil the following objectives:
   1. To identify gaps in service and thereby address the inequity currently prevailing in Wales
   2. To support future commissioning, development and planning across Wales
   3. To standardise clinical practice through the implementation of evidence based guidelines
   4. To ensure that increased awareness is supported by continuing education
   5. To strengthen multidisciplinary working.
7.3.3 Audit topics must concentrate initially on:

- Information available for Health Care Professionals
- Ease of access to services.
- Evaluating the outcomes of the prevention schemes initially in the Breast and Gynaecology cancer patients.
- Further development on discharge rates and outcome measures
- Patient satisfaction questionnaires
- Management of Cellulitis compliance to protocols and pathways
- Referral and assessment documentation audit throughout Wales
- Delayed transfers of care and discharges due to chronic oedema
- Numbers of patients receiving lymphoedema specialist treatment
- The severity of lymphoedema patients in Wales categorized into the British Lymphology Society groupings 1, 2, 3, 4

7.4 Quality of Life Tools

7.4.1 Health related quality of life measures are mainly two types, general and condition specific. A review of the literature has demonstrated that lymphoedema being a chronic, complex and multi-faceted condition has physical, psychological and social implications for the patients. In Wales, at present QOL tools are not used as part of a regular assessment in the clinical setting, however it is accepted that a reliable tool could supplement other outcome measures such as changes in limb volume. As yet, there is no condition specific QOL chronic oedema tool routinely used either for research or clinical use. There are some tools described in the literature and validated but further work is needed to establish them for use in the clinical setting. The QOL tool, LYMQUOL, was designed for routine use in clinical practice and is in the process of validation but maybe a possibility for future use.

7.5 Research

7.5.1 Improving the knowledge base is vital in lymphoedema. Research on the non cancer lymphoedemas is very important to underpin service development and ascertain true incidence and prevalence. Research and audit should be undertaken in partnership with relevant educational institutions.

7.5.2 Lymphoedema specialists studying at Masters or Doctorate level should be encouraged to engage in research that will be of benefit to the development of lymphoedema services in Wales.
<table>
<thead>
<tr>
<th><strong>Key Actions Required</strong></th>
<th><strong>By Whom</strong></th>
<th><strong>By When (end of)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Implement lymphoedema education and training packages, aimed at all levels of staff to support better management of lymphoedema / chronic oedema and reduce associated risks like cellulitis</td>
<td><strong>Co-ordination by</strong> – Project Manager</td>
<td>March 2011</td>
</tr>
<tr>
<td></td>
<td><strong>Implementation by</strong> – Local Health Boards</td>
<td>March 2012</td>
</tr>
<tr>
<td>Undertake an education and training needs analysis in each LHB enabling the implementation of the proposals in this report.</td>
<td>Project Manager</td>
<td>March 2012</td>
</tr>
<tr>
<td>Complete an audit of lymphoedema patients gaining access to assessment, treatment, cellulitis, and prevention schemes.</td>
<td>Project Manager</td>
<td>March 2011</td>
</tr>
<tr>
<td>Complete an audit of all lymphoedema referrals and documentation.</td>
<td>Local Health Boards</td>
<td>March 2011</td>
</tr>
</tbody>
</table>
Chapter 8
Lymphoedema services in Wales

8.1 Background

8.1.1 The first Welsh lymphoedema service commenced in 1995 in Wrexham and immediately accepted all types of lymphoedema referrals regardless of cause. It currently has an active case load of 600 patients and receives just over 200 new referrals every year.

8.1.2 There are currently 7 dedicated specialist lymphoedema services in Wales. Areas that do not have fully established specialist services are Powys, Ceredigion and Bridgend. The South East Wales lymphoedema service based in Velindre Hospital covers a huge unmanageable area and is massively under resourced. Patients have to travel long distances, primary/non cancer lymphoedema patients are not appropriately supported or treated and there is no dedicated accommodation in Velindre Hospital. Realistically this service needs to be divided into manageable Local Health Board areas - Aneurin Bevan, Cwm Taf and Cardiff and Vale with additional resources.

<table>
<thead>
<tr>
<th>Lymphoedema Service</th>
<th>Base</th>
<th>No of qualified staff</th>
<th>No of support staff</th>
<th>Case load</th>
<th>Prevention case load</th>
<th>Number of new referrals per year</th>
<th>WTE vs. caseload should be</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wrexham/Flintshire</td>
<td>Nightingale House Hospice Wrexham</td>
<td>2.4</td>
<td>1</td>
<td>603</td>
<td>97</td>
<td>203</td>
<td>1:251</td>
</tr>
<tr>
<td>Conwy/Denbighshire</td>
<td>North Wales cancer Centre, Glan Clwyd</td>
<td>1</td>
<td>0</td>
<td>300</td>
<td>0</td>
<td>126</td>
<td>1:300</td>
</tr>
<tr>
<td>Gwynedd/Anglesey</td>
<td>Eyr Hospital Caernarvon</td>
<td>2</td>
<td>0</td>
<td>217</td>
<td>0</td>
<td>79</td>
<td>1:109</td>
</tr>
<tr>
<td>South East Wales</td>
<td>Velindre NHS Hospital</td>
<td>5.5</td>
<td>1.5</td>
<td>2600</td>
<td>0</td>
<td>337</td>
<td>1:473</td>
</tr>
<tr>
<td>Swansea, Neath Port Talbot</td>
<td>Singleton Hospital</td>
<td>3.8</td>
<td>1</td>
<td>841</td>
<td>486</td>
<td>280</td>
<td>1:222</td>
</tr>
<tr>
<td>Carmarthenshire</td>
<td>Prince Philip Llanelli, Mynydd Mawr and Singleton Hosp</td>
<td>2</td>
<td>1.3</td>
<td>571</td>
<td>139</td>
<td>199</td>
<td>1:286</td>
</tr>
<tr>
<td>Pembrokeshire</td>
<td>Withybush Hospital</td>
<td>1.6</td>
<td>0.8</td>
<td>282</td>
<td>118</td>
<td>163</td>
<td>1:176</td>
</tr>
</tbody>
</table>

8.1.3 In Ceredigion, the breast care nurse has undergone specific lymphoedema training and offers assessment and treatment for breast cancer patients. In Bridgend the cancer lymphoedema referrals are sent to the South East Wales Lymphoedema service and the non cancer lymphoedema patients are not seen.
Although Powys does not have a dedicated lymphoedema service, Powys Local Health Board has set up a Lymphoedema Review Group. There is also a lymphoedema support service (predominantly breast cancer) running on a session basis in Bracken Trust in Llandrindod Wells and Usk House has developed a breast cancer lymphoedema prevention clinic. In North Powys Severn Hospice, Shrewsbury provides 10 hours per week to Newtown Hospital. Powys LHB provides Ystradgynlais residents access to the lymphoedema service in Abertawe Bro Morgannwg University LHB area. Overall this is patchy and inadequate and Powys needs a dedicated service with outreach clinics available locally, due to its rurality. This should be managed through the chronic conditions management model.

Local Health Boards have provided funding for lymphoedema patients to be seen by private providers, from individual patients commissioning grants. This is costly and funding could be better utilised to develop dedicated lymphoedema services. Patients needing assessment and intensive lymphoedema treatment can cost as much as £6000 per annum. Currently patients residing in Ceredigion, Rhondda Cynon Taf and Bridgend utilise private providers.

8.1.4 The majority of Lymphoedema services tend to be based or linked with cancer establishments. In the North, services are based either in hospices or within the cancer centres. The South East Wales clinic is based within the Velindre cancer centre. With growing numbers of non cancer and primary lymphoedema patients the appropriateness of being affiliated with cancer centres is questioned. Patients do not want to be reminded of their cancer treatment, or receive lymphoedema treatment at a hospice, linked with the terminally ill. In reality only 10% of a lymphoedema service workload is for palliative patients.

As many complex lymphoedema patients can have leaking lymphorrhoea, open wounds or fungating tissue voluntary sector premises are not appropriate. Additionally as lymphoedema is a specialised area volunteer organisations such as the Red Cross would not be suitable to assist. Ultimately lymphoedema is a clinical speciality where patients can have a number of other medical problems. Being coupled in the NHS environment enables lymphoedema services to have the medical support they need from dermatology, vascular and oncology consultants. This medical backing is essential in diagnosing the complex primary and non cancer lymphoedema patients whose oedema can be multi pathology.

8.2 Number of lymphoedema patients treated in Wales

8.2.1 The current data has been provided by each of the established lymphoedema services and includes the ad hoc sessions in other areas (Powys and Ceredigion (145). In 2008, there were 5,559 patients registered as having lymphoedema in Wales. Out of those 4,437 were cancer related and 1,122 are primary or non-cancer related. This data is based on the best available information to the lymphoedema clinics as there is no specific hospital returns to capture this data at present.
8.2.2 In reviewing data for the last 5 years, lymphoedema referrals are increasing significantly. In clustering services into 3 regional areas, the case load is increasing throughout Wales. This data activity is only collated on patients seen, including the prevention patients and is likely to be a huge underestimation on the total prevalence of lymphoedema in Wales as the South East Wales Service does not include non cancer referrals or lymphoedema patients in Ceredigion and Powys.

8.2.3 As a chronic life long condition ongoing treatment to maintain an individual’s lymphoedema is necessary. The graph demonstrates the rising activity levels in ABMU Local Health Board lymphoedema service since it started in 2001. The average discharge rate is 22% per year.

8.2.4 In reviewing the discharge levels in Carmarthenshire lymphoedema service for 2008-2009, 52 patients had died (10% of case load) and 82 patients were discharged (16% of the case load). A pilot reviewing outcome measure shows that:-
- Of the 82 discharged patients 42 (51%) have been referred back to the community team as they are either self managing or their oedema has resolved.
23 patients (28%) have been discharged as they have failed to turn up for an appointment and did not respond to ‘Did Not Attend’ letters.

12 patients (15%) refused treatment

3 patients (4%) were inappropriate referrals thus returned to source.

Of the discharges 46% were breast cancer referrals, 18% were from oncology and 36% were primaries or non cancers.

8.3 Waiting times, data collection and targets

8.3.1 The Welsh Association of Lymphoedema Services collects annual data on numbers of patients waiting for an appointment. On March 31st 2007, 294 patients were waiting for an appointment. This number reduced slightly in 2008 with 244 patients. Latest figures for 2009 are well over 300 waiting patients. This appears to demonstrate there is unmet need for lymphoedema patients.

8.3.2 Data collection for lymphoedema is inadequate throughout Wales. No universal or agreed data set exists, thus patient needs, waiting times and demands on services are only captured at a local level. Clinical data must be collected throughout Wales to include the following:-

- New referrals
- follow up appointments
- intensive treatments
- Domiciliary Visits
- UTA/CAN
- DNA

This information could be linked to the LymCalc computer programme which could extract all the data required for audit purposes and can be collected on actual lymphoedema incidence and prevalence as well as referral data in each of the Local Health Boards.

8.4 Lymphoedema service provision- What is needed?

8.4.1 Correct diagnosis and treatment is fundamental in any model of service. Patients and health care professionals need to be more aware of symptoms and early recognition. The Chronic Conditions Management (CCM) Service Improvement Plan - 2008-2011 identifies the actions needed to implement the CCM Model and Framework, improving prevention and the care of those living with chronic conditions as well as supporting people’s independence in all areas of life. ¹

8.4.2 Each Local Health Board must establish or improve dedicated lymphoedema services in their locality. Lymphoedema services must be sited in NHS Hospital environments with appropriate local community clinics established in line with the ‘Rural Health planning – improving service delivery across Wales’ published in 2009. Services should operate on a weekly daily basis. New services that need to be developed include:
<table>
<thead>
<tr>
<th>Health Board</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Powys</td>
<td>o Brecon War Memorial Hospital or Bronllys with supported clinics at Newtown Hospital and Llandrindod Wells</td>
</tr>
<tr>
<td>Hywel Dda</td>
<td>o Bronglais Hospital, Aberystwyth with clinics in Cardigan/Newcastle Emlyn</td>
</tr>
<tr>
<td>Abertawe Bro Morgannwg</td>
<td>o Princess of Wales Hospital Bridgend</td>
</tr>
<tr>
<td>Cwm Taf</td>
<td>o Royal Glamorgan Llantrisant and/or o Prince Charles Merthyr</td>
</tr>
<tr>
<td>Cardiff &amp; Vale</td>
<td>o University Hospital of Wales</td>
</tr>
<tr>
<td></td>
<td>o Llandough Hospital with additional local community sessions</td>
</tr>
<tr>
<td>Aneurin Bevan</td>
<td>o Neville Hall, Abergavenny with additional community sessions at Ystrad Mynych &amp; Chepstow</td>
</tr>
</tbody>
</table>

8.4.3 The optimum number of lymphoedema patients per therapist in treating all categories of lymphoedema including prevention, education and awareness should be 150. This is based on the chronic and severe nature of the condition and therapists maintaining their expertise by seeing a high volume of patients. In reviewing statistics each therapist on average sees annually:-

- 70 new patients
- 500 follow up sessions
- 200 treatment sessions
- 15 Home Visits

Seeing high volumes of patients means that education, audit, research and continuous personal development can suffer as a consequence.

As can be seen in 8.1.2 the whole time equivalent versus caseload in every service bar one is well over the guidelines of 1:150. The biggest staffing ratio is in South East Wales where 1 therapist sees 473 patients nearly 3 times the amount. This shows that evidence based practice and treatment is not being achieved with these high numbers. Lymphoedema services must also operate with an appropriate skill mix, including lymphoedema assistants/healthcare workers and administration staff. Modernising lymphoedema delivery will call for innovation ways of working to optimise existing roles, the development and expansion of skills and competencies.

8.4.4 Actual lymphoedema prevalence in Wales is 2 per 1000. Taking 150 patients per therapist, guidance requires 36 qualified practitioners. The introduction of non qualified assistants and administration staff will free up qualified staff time to complete more of the specialist tasks. This would enable them to see 200-220 patients as well as initiating prevention and education schemes, audit and research. Based on the statistics, extra staffing sessions have been included for rural areas in line with ‘Rural Health planning – improving service delivery across Wales.’ Provision is made to backfill for lymphoedema leads’ dedicated time, with assistant cover.
Based on this analysis, Wales needs a minimum of 27.3 WTE qualified or training lymphoedema specialist/practitioners working to the agreed guidelines, care pathways and protocols. These qualified members of staff will be of a suitable skill mix ranging from AFC band 5 to band 8A. 18.3 WTE posts already exist thus an additional 9 WTE are required.

* The SE Wales Lymphoedema service hosted by Velindre NHS Trust has 5.5 qualified staff for Cwm Taf, Cardiff & Vale and Aneurin Bevan. It requires an additional 4 members of staff.

8.4.5 Wales needs 17.6 WTE lymphoedema assistants and administration support. These posts will work jointly with the qualified members of staff freeing up lymphoedema practitioners' time from more routine duties and assist in the data collection. Currently there are only 5.6 WTE assistants. An additional 12 WTE are required. This figure has been based on the prevalence data and recommendations on skill mix from the International Lymphoedema Framework Project.

* The SE Wales Lymphoedema service hosted by Velindre NHS Trust has 1.5 qualified staff for Cwm Taf, Cardiff & Vale and Aneurin Bevan. It requires an additional 4.5 members of staff.
8.4.6 Staffing needs are based on actual prevalence in Wales, which is expected to rise sharply once other clinics have been established. The 21 WTE extra members of staff will manage workload at 2 per 1000. If the number increases significantly further investment may be needed in the future.

8.4.7 To implement the all Wales level key actions and drive forward implementation of the Strategy a lymphoedema project manager must be appointed, initially for two years. The post will coordinate and work alongside the LHB planning and delivery teams to help develop new and existing lymphoedema services to ensure equity of access for all lymphoedema sufferers.

8.5 Resources

8.5.1 Lack of treatment for lymphoedema patients can lead to:
- Increased swelling
- Pain
- Tissue and skin breakdown
- Irreversible damage to the lymphatics
- Recurrent infections
- Admissions to hospitals
- Inability to work
- Reduced psychological well being and quality of life

Potential cost savings can be realised from more effective management of lymphoedema patients, particularly in relation to hospital admissions for cellulitis, wasted prescriptions and community nurse staffing costs. Appropriate and better lymphoedema management will improve quality of life increasing their ability to work and reducing associated disability benefits.

8.5.2 Capital investment may be required to provide appropriate accommodation for lymphoedema services, to ensure suitable clinic space is available to allow services to function at full capacity. Expenditure will also be needed for calculators and Information Technology equipment for data collection.

8.5.3 In order to provide a high standard of lymphoedema care additional staff and services need to be developed. The recruitment of 21 WTE in total will enable all patients with lymphoedema to access lymphoedema services regardless of cause addressing the current patchy and inequity of services.

8.5.4 In order to maximise the efficiency and effectiveness of lymphoedema services, an all Wales purchasing of garments protocol needs to be explored. Compression garments are the mainstay of lymphoedema management and patients are issued with hosiery every 4 to 6 months. Prices of garments vary from an arm sleeve at £20 to a made-to-measure pair of tights at £350. This is usually dependent on the type of material and compression class of garment required. The average spend per patient on compression garments is £125. Not all garments are available on prescription. Those that are could be suitable for the ‘at risk groups’ and mild lymphoedemas. Training is urgently required to educate primary care staff on the different types of
garments available, when ordering such garments. Currently no fixed discounts occur with any of the suppliers or manufacturers. Mainstreaming discounts will be financially advantageous.

8.5.5 Greater attention to wasted resources as a consequence of developing lymphoedema and cellulitis needs to be investigated and audited. Cellulitis care pathways and protocols must be developed and adhered to.

8.5.6 Education programmes for all health care professionals including primary care and cancer teams, will need to be funded. Appropriately trained district and practice nurses, including GPs will have an important role in identifying the unmet need in the community. Lymphoedema services and the lymphoedema planning and delivery groups for each of the health boards should be responsible for providing lymphoedema awareness sessions throughout their locality.

<table>
<thead>
<tr>
<th>Key Actions Required</th>
<th>By Whom</th>
<th>By When (end of)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop and implement lymphoedema data sets that can be utilised throughout Wales via the LymCalc computer programme. Consideration to be given for data to be reviewed and monitored as part of the Diagnostic and Therapy waiting time targets</td>
<td>Developed by Project Manager</td>
<td>March 2011</td>
</tr>
<tr>
<td></td>
<td>Implemented by Welsh Assembly Government, Local Health Boards</td>
<td>March 2012</td>
</tr>
<tr>
<td>Report annually on levels of lymphoedema clinical outcome codes and make recommendations based on audit findings to further improve lymphoedema services</td>
<td>Local Health Boards</td>
<td>March 2012</td>
</tr>
<tr>
<td>Review existing lymphoedema compression garment protocols with a view to instigating central procurement of garments to reduce costs.</td>
<td>Project Manager</td>
<td>March 2011</td>
</tr>
<tr>
<td>Develop key quality indicators to assess the quality of care being provided</td>
<td>Developed by - WALS</td>
<td>March 2010</td>
</tr>
</tbody>
</table>

8.9 Conclusion

8.9.1 Lymphoedema is a physically, psychologically and socially debilitating life-long chronic condition. Treatment enables patients to return to independent productive lives. It reduces the burden on health and other services, by reducing the number of hospital admissions and the cost of treating complications such as cellulitis and reducing the needs on community services and practice nurses.
Appendix A

Acknowledgements

The Welsh Assembly Government would like to thank all key stakeholders that have contributed to the development of this Lymphoedema Strategy. Special thanks are made to Melanie Lewis and Eilish Lund for their commitment to this publication.
## Appendix B

### Summary of Key Actions

<table>
<thead>
<tr>
<th>Key Actions Required</th>
<th>By Who</th>
<th>By When (End of)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Planning</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Appoint an all Wales Project Manager, for 2 years, to lead and champion the implementation of the Strategy</td>
<td>Local Health Boards working and funding collaboratively</td>
<td>March 2010</td>
</tr>
<tr>
<td>2. Plan, secure and deliver high quality lymphoedema services for assessment and management to meet the needs of both cancer and non cancer patients</td>
<td>Local Health Boards Velindre NHS Trust and Voluntary Sector</td>
<td>March 2011</td>
</tr>
</tbody>
</table>
| 3. Develop Evidence based lymphoedema care pathways and implement across all health care settings to manage lymphoedema and the obstacles to recovery | Developed by – Project Manager  
Implemented by - Local Health Boards, Velindre NHS Trust and Voluntary Sector | March 2011  
March 2012 |
| 4. Review and standardise patient information leaflets on preventative strategies and self management | Developed by - Project Manager  
Implemented by - Local Health Boards | March 2011  
March 2012 |
| 5. Implement education and training packages for all health care professionals to support better management of lymphoedema and reduce associated risks | Developed by – Project Manager  
Implemented by - Local Health Boards | March 2011  
March 2012 |
| **Prevention and reducing the risk**                                                 |                                                                        |                  |
| 1. Develop evidence based cellulitis care pathways and implement use across all health care settings | Developed by – Project Manager, WALS  
Implemented by - Local Health Boards, Velindre NHS Trust and Voluntary Sector | March 2011  
March 2012 |
| 2. All breast cancer patients must have access to lymphoedema prevention and education schemes to reduce their risk of developing lymphoedema. | Implemented by – Local Health Boards                                  | March 2011       |
| 3. All lymphoedema services in conjunction with physiotherapy and dietetics must offer an active management programme for obese patients. | Implemented by – Local Health Boards                                  | March 2012       |
| **Diagnosis and Assessment**                                                        |                                                                        |                  |
| 1. Develop all Wales assessment tools and referral forms for implementation and use across all lymphoedema services in Wales | Developed by – Project Manager | March 2011 |
| | Implemented by – Local Health Boards, Velindre NHS Trust, GPs and Voluntary Sector | March 2012 |
| 2. Develop and implement lymphoedema referral protocols and criteria supported by appropriate training across all health care settings to aid early assessment and diagnosis of lymphoedema | Developed by - Project Manager | March 2011 |
| | Implemented by – Local Health Boards, Velindre NHS Trust, GPs and Voluntary Sector | March 2012 |
| 3. Undertake an evaluation of current services to identify good practice to be disseminated to all areas across Wales to aid service improvements | Project Manager | March 2011 |

**Management of Lymphoedema**

| 1. Assess and review the ongoing needs of lymphoedema patients in conjunction with chronic condition management | Local Health Boards | March 2011 |
| 2. Establish community lymphoedema sessions for lesser complex patients to be delivered in community hospitals /GP surgeries | Local Health Boards Primary Care | March 2012 |
| 3. Establish a Lymphoedema Link Nurse Scheme, within each community health care team, to facilitate collaboration. | Local Health Boards | March 2011 |

**Facilitating and Managing Independence**

| 1. Individual patient care plans must include a category for:-
\[\checkmark\] self management
\[\checkmark\] access to weight reduction programmes
\[\checkmark\] signposting patients to Expert Patient Programmes | Local Health Boards | March 2011 |
<p>| 2. Review appropriate information and support groups available for all lymphoedema/chronic oedema enabling patient signposting | Local Health Boards | March 2011 |
| 3. Ensure unpaid carers are actively involved in joint care planning for both care of the patient and their safety to prevent stress or injury to themselves | Local Health Boards | March 2011 |</p>
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<th><strong>Education, Audit and Research</strong></th>
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<tbody>
<tr>
<td>1. Implement lymphoedema education and training packages, aimed at all levels of staff to support better management of lymphoedema / chronic oedema and reduce associated risks like cellulitis</td>
<td><strong>Co-ordination by</strong> –Project Manager</td>
<td>March 2011</td>
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<td><strong>Implementation by</strong> Local Health Boards</td>
<td>March 2012</td>
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<tr>
<td>2. Undertake an education and training needs analysis in each LHB enabling the implementation of the proposals in this report.</td>
<td>Project Manager</td>
<td>March 2012</td>
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<tr>
<td>3. Complete an audit of lymphoedema patients gaining access to assessment, treatment, cellulitis, and prevention schemes.</td>
<td>Project Manager</td>
<td>March 2011</td>
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<tr>
<td>4. Complete an audit of all lymphoedema referrals and documentation.</td>
<td>Local Health Boards</td>
<td>March 2011</td>
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<th><strong>Service Provision</strong></th>
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<tr>
<td>1. Develop and implement lymphoedema data sets that can be utilised throughout Wales via the LymCalc computer programme. Consideration to be given for data to be reviewed and monitored as part of the Diagnostic and Therapy waiting time targets</td>
<td><strong>Developed by</strong> Project Manager</td>
<td>March 2010</td>
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<td></td>
<td><strong>Implemented by</strong> Welsh Assembly Government, Local Health Boards</td>
<td>March 2012</td>
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<tr>
<td>2. Report annually on levels of lymphoedema clinical outcome codes and make recommendations based on audit findings to further improve lymphoedema services</td>
<td>Local Health Boards</td>
<td>March 2012</td>
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<tr>
<td>3. Review existing lymphoedema compression garment protocols with a view to instigating central procurement of garments to reduce costs.</td>
<td>Project Manager</td>
<td>March 2011</td>
</tr>
<tr>
<td>4. Develop key quality indicators to assess the quality of care being provided</td>
<td><strong>Developed by</strong> - WALS</td>
<td>March 2010</td>
</tr>
</tbody>
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Appendix C

References

Clinical Resource Efficiency Support Team (CREST) Leg Ulcer Management


Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children.2006 NICE:CG43


92 A review of Lymphoedema Services in Wales (2003) Cancer Services Commissioning Group


Appendix D

Glossary

**Cellulitis:** A sudden, non-contagious infection of the skin, characterised by redness, swelling and heat, accompanied by pain and tenderness

**Chylous Reflux:** A reflux of intestinal lymph, which is white in colour, on to the skin in the form of a fistula or white vesicles which leak when damaged.

**Decongestive Lymphoedema Therapy:** Consists of a daily treatment programmes which may include MLD/SLD, MLLB, skin care and exercise

**Filariasis:** Lymphatic filariasis is caused by parasitic tissue-dwelling filarial nematode worms which are endemic to the tropics

**Hyperkeratosis:** A build up of horny scales on the surface of the skin

**Klippel-Trenaunay Syndrome:** Characterised by hypertrophy of all tissues including the bones, varicose veins arterovenous fistulas and insufficiency of the lymphatics

**Manual Lymphatic Drainage:** (MLD) is a gentle type of skin massage carried out by trained therapists. The aim is to enhance the removal of proteins from tissues and increase lymphatic flow.

**Multi Layer Lymphoedema Bandaging:** (MLLB) A layer of stockinette followed by various types of soft padding and foam with short stretch bandages applied evenly over the top to give a semi-rigid support to the limb

**Lymphadenitis:** An inflammatory condition of the lymph nodes

**Lymphangiomata:** Consists of extremely dilated lymphatic vessels in the skin which bulges on to the surface giving the appearance of a blister, some forming a tumour-like mass. They may burst and leak fluid or over time change to form thick skin nodules

**Noonan Syndrome:** A multiple congenital anomaly syndrome, caused by a mutation in a single gene. Characteristics include short stature, neck webbing and congenital cardiac anomalies. Lymphoedema is usually present at birth but the age of onset may vary

**Milroys Disease:** Known as hereditary lymphoedema type 1. Usually present at birth or before puberty. It comprises swelling of the legs and may involve the genitalia arms and face

**Pappilomatosis:** Cobblestone-like projections of the skin surface indicating dilated skin lymphatics surrounded by fibroed tissue
**Perometry:** Electronically gathered data that is used to calculate limb volume.

**Sarcoidosis:** A multi-system disorder of unknown origin characterised by the appearance of granulomas in the lungs or the lymph nodes.

**Sarcoma:** A malignant growth of the soft tissues.

**Sentinel Node Biopsy:** Used in breast cancer surgery to determine the extent or stage of cancer, because it involves the removal of fewer lymph nodes than the standard procedure the potential for side effects such as lymphoedema is lower.

**Simple Lymph Drainage:** SLD is based on the principles of MLD and is applied by the patient themselves, their carer or by the therapist and is used daily as part of a lymphoedema treatment programme.

**Turners Syndrome:** A congenital chromosomal abnormality found only in women characterised by webbed neck dwarfism, retarded maturation of the skeleton, congenital heart disease and lymphoedema.