

Lymphoedema: A guide for clinical services



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A priority for the ACI is identifying unwarranted variation in clinical practice and working in partnership with healthcare providers to develop mechanisms to improve clinical practice and patient care.

www.aci.health.nsw.gov.au

AGENCY FOR CLINICAL INNOVATION

Level 4, 67 Albert Avenue
Chatswood NSW 2067

PO Box 699 Chatswood NSW 2057

T +61 2 9464 4666 | F +61 2 9464 4728

E aci-info@health.nsw.gov.au | www.aci.health.nsw.gov.au

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Acknowledgements

Working group

Brenda Svensson	Lymphoedema Specialist Occupational Therapist, Lourdes Hospital Dubbo
Clare Eastment	Lymphoedema Physiotherapist, Illawarra Shoalhaven Local Health District
Debbie Geyer	General Practitioner / Consumer; Lymphoedema Support Group NSW
Elizabeth Dylke	Researcher, University of Sydney
Heather Batt	Occupational Therapist, Bathurst
Helen Mackie	Lymphoedema and Rehabilitation Medical Specialist, Mt Wilga Private Hospital and Macquarie University Hospital
Jane Maher	Lymphoedema Specialist Occupational Therapist, Concord Hospital
Jenny Caspersenn	Manager, Chronic Care Network, ACI (Convenor)
Jessica Allchin	Occupational Therapist, Sydney Local Health District
Johanna Newsom	Physiotherapist, Sydney Children's Hospital Network
Kimmi Katte	Consumer
Louise Koelmeyer	Lymphoedema Specialist Occupational Therapist, Macquarie University Hospital
Lynne Brodie	Manager, Transition Network, ACI
Stella Koukoullis	Consumer
Sue Steele-Smith	Senior Program Officer, Allied Health, Health Education and Training Institute

Reference group

Anne Smith	Physiotherapy Head of Discipline, Illawarra Shoalhaven Local Health District
Dianne Green	Breast Care RN, Western NSW Local Health District
Fiona Willington	Physiotherapist, Sydney Children's Hospital Network
Gillian Neil	Breast Care RN, Royal Hospital for Women and Prince of Wales Hospital
Helen Conlon	Breast Care RN, Royal Hospital for Women and Prince of Wales Hospital
Jacqueline Dominish	Principal Allied Health Advisor, Workforce Planning and Development, NSW Ministry of Health
Joanne Wright	Psychiatrist (old age specialist), SWELL Kids
Leanne Larsson	Occupational Therapy Manager, Gosford Hospital
Lissa Spencer	Senior Physiotherapist, Royal Prince Alfred Hospital
Margaret Patterson	Physiotherapist, Sydney Children's Hospital Network
Marianne McCormick	Physiotherapist, Sydney Children's Hospital Network
Mark Malouf	Surgeon, Phlebologist
Michelle Coore	Acting Allied Health Initiatives Manager, Western NSW Local Health District
Nerissa Morley-Coulls	Lymphoedema Specialist Physiotherapist, Broken Hill
Rebecca Hudson	Occupational Therapist, Spina Bifida Adult Resource Team, Northcott
Robyn Sierla	Senior Occupational Therapist, Royal Prince Alfred Hospital
Sharon Kilbreath	Professor, Deputy Dean, Academic Discipline of Physiotherapy, Faculty of Health Sciences, University of Sydney

The clinicians, health professionals and consumers who participated in the creation of this document acknowledge that they are also representatives on other bodies. These include professional bodies, consumer advocacy groups and research organisations.

Glossary

Australasian Lymphology Association	Australasian peak professional body promoting best practice in lymphoedema management, education and research.
Baker's cyst	A fluid filled cyst on the back of the knee caused by an abnormal collection of fluid in the bursa.
Bioimpedance spectroscopy	An assessment tool that measures resistance to an electrical current to determine extracellular fluid volume. It may allow earlier detection of breast cancer-related lymphoedema than circumferential measures ³⁵ and can allow tracking of lymphoedema progression over time. BIS measurement results are often reported as an inter-limb ratio between an affected and unaffected limb. If certain manufacturers' devices are used (Impedimed U400 or XCA), these ratios may be converted into an L-Dex (lymphoedema index) score.
Cellulitis	An acute spreading bacterial infection of the dermis and subcutaneous tissues. It causes local signs of inflammation, such as warmth, erythema, pain, lymphangitis, and frequently systemic upset with fever and raised white blood cell count.
Collateral vein	A vein that develops as an alternative circulation pathway around a blocked vein.
Cochrane Review	An internationally recognised systematic review of primary health care research, investigating the impact of interventions for prevention, treatment and rehabilitation.
Enable NSW	A division of HealthShare NSW that provides aids and equipment such as wheelchairs, ventilators, prosthetic limbs and consumable items for people living with disability or chronic health conditions.
Filariasis	A tropical, parasitic disease that affects the lymph nodes and lymph vessels. It is one of the primary causes of lymphoedema worldwide.
HETI trained health professional	A health professional who has completed the HETI online modules <i>Lymphoedema Awareness</i> and <i>Lymphoedema Early Intervention</i> .
NLPR Level 1 Lymphoedema trained health professional	A health professional who has completed the Level 1 course, which provides the basic skills and knowledge to assess and treat uncomplicated lymphoedema.
NLPR Level 2 Lymphoedema trained health professional	A health professional who has completed the Level 2 course, which provides the training to assess and treat all forms of lymphoedema, including complex presentations.
L-Dex (lymphoedema index)	A measure of the extracellular fluid in a limb. This assists with early detection and determining progression of lymphoedema by tracking changes in an at-risk limb. It is measured using bioimpedance spectroscopy devices (BIS).
Lipoedema	A syndrome of painful fatty legs in women (only) characterised by symmetrical, non-pitting fatty enlargement of the legs, thighs and buttocks but not feet, with tenderness and bruising.
Lymph fluid	A clear fluid located outside the cell walls. It contains water, lipids, proteins derived from the blood and body cells and products of cell metabolism. The lymphatic vessels transport lymph back to the blood circulation.
Lymphangitis	Acute lymphangitis is a bacterial infection in the lymphatic vessels, characterised by painful, red streaks below the skin surface.
Lymphoedema	Swelling of a body region due to the accumulation of extracellular fluid in the interstitial tissue as a result of lymphatic system failure. ^{6, 51} Once established, it is a progressive chronic condition.
Lymphoedema practitioner	A practitioner who fulfils the accreditation requirements of the ALA and is eligible to be listed on the NLPR.
Lymphorrhoea	A leakage of lymphatic fluid from the skin surface.
Lymphovenous oedema	A condition commonly occurring in obese, immobile people with an underlying pathology of venous insufficiency. Often coexists with and complicates lymphoedema and can cause skin weeping and ulceration.

National Lymphoedema Practitioners Register	The NLPR, maintained by the ALA, is a non-mandatory public register of lymphoedema practitioners who have completed ALA-accredited lymphoedema management training in Australia and New Zealand.
Patient	A person who is at risk of or has been diagnosed with lymphoedema.
Primary lymphoedema	Lymphoedema without an inciting factor, termed primary lymphoedema, is generally due to a congenital or inherited condition associated with pathologic development of the lymphatic vessels. There are many forms of primary lymphoedema. It often presents in childhood, but later presentations into early and later adulthood also occur.
Secondary lymphoedema	Lymphoedema that occurs as the result of other conditions or treatments, such as cancer treatment, infection, inflammatory disorders, obesity, and chronic forms of lymphatic overload (e.g. chronic venous insufficiency, trauma/burns).
Stemmer's sign	Stemmer's sign is a clinical assessment used in the diagnosis of lymphoedema. A positive result occurs when a thickened fold of skin at the base of the second toe or second finger cannot be gently pinched and lifted. The presence of this sign is most often an early diagnostic indication of primary lymphoedema; however, it can also develop later in secondary lymphoedema.
Toe web intertrigo	An inflammation due to bacterial, fungal or viral infection occurring in opposing skin surfaces, in this case between toes.

Abbreviations

ACI	Agency for Clinical Innovation
ALA	Australasian Lymphology Association
ABPI	Ankle-brachial pressure index
BCRL	Breast cancer-related lymphoedema
BIS	Bioimpedance spectroscopy
CLT	Complex lymphoedema therapy
DVT	Deep vein thrombosis
GP	General practitioner
HETI	Health Education and Training Institute
ILF	International Lymphoedema Framework
LHD	Local health district
LLLT	Low level laser therapy
MLD	Manual lymphatic drainage
NDIS	National Disability Insurance Scheme
NLPR	National Lymphoedema Practitioners Register (a register of ALA-accredited lymphoedema therapists)
NSW	New South Wales
PHN	Primary health network
SIPC	Sequential intermittent pneumatic compression
SHN	Specialty health network

Contents

Acknowledgements	ii
Glossary	iii
Abbreviations	vi
Executive summary	1
Development of this document	2
Introduction to Lymphoedema	4
Principle 1: Early identification, education and monitoring of patients at risk of lymphoedema	7
Principle 2: Identification, assessment and diagnosis of lymphoedema by a trained health professional	10
Principle 3: Patient-centred education to enable self-management of lymphoedema	15
Principle 4: Comprehensive treatment tailored to patient needs and clinical reasoning	17
Principle 5: Correct provision of compression garments according to clinical recommendations	20
Principle 6: Effective management of lymphoedema-associated cellulitis, including prevention of recurrence	22
Principle 7: Effective response to inpatients with lymphoedema	24
Conclusion	26
References	27
Other resources	29
Appendix 1: Comparative guidelines/accepted practice protocols	31
Appendix 2: Lymphoedema treatment description and applications	32
Appendix 3: LHD self-assessment tool	34

Executive summary

Lymphoedema is a chronic swelling of a limb or body region and is associated with significant morbidity, loss of function and, on rare occasions, mortality. Poor management of lymphoedema can have detrimental effects on a person's physical and psychosocial health. Pain and discomfort are frequent symptoms, and people with lymphoedema have increased susceptibility to acute cellulitis, requiring hospitalisation and antibiotic therapy.

The Agency for Clinical Innovation (ACI) has developed *Lymphoedema: A guide for clinical services* to identify best-practice management of lymphoedema as shown in the following seven principles.

Principle 1: Early identification, education and monitoring of patients at risk of lymphoedema

Principle 2: Identification, assessment and diagnosis of lymphoedema by a trained health professional

Principle 3: Patient-centred education to enable self-management of lymphoedema

Principle 4: Comprehensive treatment tailored to patient needs and clinical reasoning

Principle 5: Correct provision of compression garments according to clinical recommendations

Principle 6: Effective management of lymphoedema-associated cellulitis, including prevention of recurrence

Principle 7: Effective response to inpatients with lymphoedema

This document will provide guidance for local health districts (LHDs), speciality health networks (SHNs) and health professionals to support optimal care for people affected by lymphoedema across NSW. Early identification is essential for effective lymphoedema management. Accurate assessment should be accompanied by individualised care plans with appropriate, evidence-based treatments.

Developing comprehensive integrated lymphoedema services that identify people at risk will enhance timely and responsive treatment. This will enable people to remain active, self-manage their condition and reduce the likelihood of complications.

This guide for best practice in lymphoedema management aims to raise awareness of the condition and improve outcomes for people living with or at risk of lymphoedema in NSW.

Development of this document

Previous work by the NSW Health Education and Training Institute (HETI) identified the critical nature of early intervention for lymphoedema, variable consumer experiences and high costs in NSW for inpatient admissions for cellulitis. Information provided by LHDs indicated lymphoedema services were not consistently available in all districts. In 2015 HETI launched two online training modules to enhance the knowledge and skills of health professionals. Twenty-four occupational therapists and physiotherapists were funded in 2015 to attend National Lymphoedema Practitioners Register (NLPR) Level 1 specialist lymphoedema training. A further 22 specialist training positions were funded in 2017.

This document was developed in 2017 under the auspices of the ACI's Chronic Care Network. A broad reference group was established which included people living with lymphoedema, medical, nursing and allied health professionals from both regional and metropolitan settings, representatives from non-government organisations, and academics. Wide consultations and review processes further refined the document.

Lymphoedema: A guide for clinical services is supported, where available, by current evidence. Where evidence is unavailable or conflicting, recommendations for best practice are based on consensus from experts in the reference group. Full references are available in the list of references.

Aims

This document specifies the principles of care that will guide NSW health services to deliver effective early identification, high quality management and care for people living with, or at risk of developing, lymphoedema.

By clearly describing best-practice principles of care, it is hoped that:

- unwarranted variations can be reduced
- clinical practice will increasingly align with research evidence
- poor consumer experiences and unmet needs will be addressed
- people with lymphoedema will be better able to manage their condition
- standards of care will improve.

Objectives and intended audience

This document can be used as a resource for NSW health professionals to enhance their practice in the early identification, management and care of lymphoedema clients. This may be particularly valuable for those who are new to this specialist area of practice, or those seeking to improve their practice in keeping with current optimum standards of care and available evidence.

Importantly, this document can also guide LHDs and SHNs in NSW to improve or, in some areas, establish services for people living with lymphoedema. The document may also be used as a self-assessment tool for health services to identify areas for improvement necessary to meet desirable quality of care in NSW.

The principles of care outlined in this guide are not intended to replace informed clinical judgment, nor prescribe how a healthcare service should meet these principles. The approach different services, and the clinicians working within them, take to meet these principles should be customised, in a patient-focused way, to address the diversity of the health care settings and the resources available to them.

Scope

The guide aims to cover the care for people with a broad spectrum of lymphoedema classifications in clinical settings. This includes: primary lymphoedema (including lymphoedema in paediatric clients), secondary lymphoedema, and lymphoedema in palliative care settings.

Many people develop lymphoedema secondary to other conditions, such as stroke, spinal injury, obesity and spina bifida. For example, lymphoedema is almost 100 times more prevalent in people with spina bifida than in the general patient population.² Another example is lymphovenous oedema, which commonly occurs in the legs of people with obesity who are immobile and deconditioned. While the principles outlined in this framework are applicable to these groups, there are likely to be additional needs and considerations that are outside the scope of this document.

While this document is publicly available, it is targeted at health professionals and uses language in keeping with that audience.

Benefits

The benefits of implementing the principles of care recommended in this document include:

- increased awareness of lymphoedema and the benefits of early detection
- more accessible, improved treatment services for people who have lymphoedema
- greater capacity for self-management
- reduced financial impact on the health system, and importantly,
- better outcomes for patients.

Style note

Paediatric considerations are indicated by

- 😊 blue text and happy child bullets or
- 😊 a box with a blue-background heading and a child icon.



PAEDIATRIC CONSIDERATIONS

Example of paediatric-specific content, such as a case study or resources.

Introduction to lymphoedema

Lymphoedema is a chronic swelling of one or more limbs or body regions, such as the arms, legs and neck, breast or genitals.³⁻⁵ Lymphoedema occurs when there is an imbalance in the transportation and/or production of fluid in the interstitial tissues, resulting in the accumulation of extracellular fluid.⁶ It may be a congenital malformation of the lymphatic system (primary lymphoedema) and/or due to damage, trauma or interference with the lymphatic vessels or nodes, for example after cancer treatment (secondary lymphoedema). While lymphoedema starts as a fluid-focused condition, for some, it can progress to accumulation of adipose and/or fibrotic tissue in affected regions. This change in tissue composition is also known as staging, with lymphoedema currently divided into four stages depending on the progression of the tissue changes (Stage 0 through to Stage III; [see Table 2](#) on page 12).⁶

Regardless of the stage of presentation or the type (primary or secondary), lymphoedema is a chronic and permanent condition, requiring ongoing care and management. Lymphoedema not only impacts a person's physical, psychological and social functioning⁷⁻⁹, but it also puts them at higher risk of developing cellulitis, an infection of the skin and subcutaneous tissue.¹⁰ In 2015-16, cellulitis was identified as the most preventable cause of admission to NSW hospitals.¹¹

Conservative estimates, based on UK prevalence studies¹², suggest there may be 70,000 people in Australia living with lymphoedema, with 22,000 in New South Wales. There is evidence that lymphoedema is under-reported and the actual numbers may be higher.¹³

Improvements need to be made to address a lack of awareness of lymphoedema among clinicians, policy makers and the general public; training needs for clinicians, particularly in rural areas; a lack of adequate funding for services; and no centralised policies for lymphoedema management at a state or federal level.^{14, 15}

Lymphoedema care requires a multidisciplinary approach that can include general practitioners (GPs), surgeons, physicians, physiotherapists, occupational therapists, nurses, dietitians, podiatrists, counsellors and service managers, among others.

Effects of lymphoedema

Physical effects

Lymphoedema can cause pain, and decreased limb movement and mobility. It can cause problems with dressing and other activities of daily living.¹ Oversized clothing and footwear, needed to accommodate a swollen limb or body part, present fall risks and significant difficulties in mobilisation. Lymphoedema may also cause chronic skin changes, reducing the skin's ability to act as a barrier to infections (cellulitis) and increasing the challenges of treating wounds. Left untreated, patients with lymphoedema are twice as likely to develop cellulitis requiring hospitalisation and intravenous antibiotic therapy.^{16, 17}

Psychological effects

Lymphoedema may affect a person's psychological health, resulting in negative body image, emotional disturbances, anxiety and depression, as well as social isolation.^{18, 19} In a national survey, supported by Breast Cancer Network Australia, a diagnosis of lymphoedema impacted work, family life, self-image and feelings.²⁰ The greater the severity of lymphoedema, the higher the impact on the individual.¹⁹

- ☺ **Adolescents and young people with lymphoedema also experience issues with social inclusion and participation with peers, poor self-image and emotional disturbances.**²¹
- ☺ **Further challenges identified for the families of children with lymphoedema include: altered relationships between parents and children with lymphoedema (moving between being a parent, an advocate, and a proxy health professional), as well as altered relationships between siblings (jealousy and time availability, also increased expectations of responsibility and maturity, particularly for older siblings without lymphoedema).**^{22, 23}

Economic effects

People living with lymphoedema describe the cumulative costs of practitioner fees, compression garments and skin and wound care products.^{1, 14} People with lymphoedema also report needing to take leave from work or having their employment affected.²⁰ More serious cases can result in long-term disability and unemployment.²⁴

Hospital admissions for cellulitis requiring intravenous antibiotic therapy result in substantial, and potentially avoidable, costs to the health care system.^{16, 17}

- ☺ **Carers also need to take time away from work and other responsibilities if a dependent has lymphoedema.**

Aboriginal people

In general, Aboriginal people experience poorer health outcomes than the broader population, particularly with respect to chronic conditions. The causes are multifactorial and often result in Aboriginal people presenting to health services late in the course of their disease, which in turn leads to significantly higher rates of complications and death.

There is no specific data on the prevalence of lymphoedema in Aboriginal people.²⁵ Anecdotal reports from lymphoedema allied health managers in regional areas of NSW suggest the incidence is not higher. However, barriers such as poor access to services and therefore the ability to maintain regular treatments are real.

Some challenges include:

- socioeconomic factors involving affordability, availability and follow up
- limited access to a regular GP
- poor levels of health literacy within communities
- poor adherence to treatments such as using compression garments in hot climates
- a lack of identification with public health services by Aboriginal clients.

One manager reported 'the progression from early signs to a chronic condition is more common and long-term management less effective as our Aboriginal clients tend to seek treatment later and not engage with services until they have significant pain or infection. Their treatment often requires hospitalisation for management of cellulitis or, in some cases, sepsis.'

Another said, 'Based on our experience with other chronic diseases, the barriers and issues Aboriginal people experience have a significant impact on their ability to access appropriate assessment and maintain the very intensive and thorough interventions that are required to identify, treat, and manage lymphoedema.' She continued: 'access to lymphoedema services across NSW Health for non-Aboriginal people is limited and is in high demand so it would be difficult to provide additional, specialised services for Aboriginal people to address some of those barriers.'

Implementation activities to improve services for Aboriginal people should reflect cultural sensitivity and appropriateness, with an emphasis on trust and mutual respect.

Considerations such as flexible service delivery, reducing out-of-pocket costs and ensuring the involvement of local Aboriginal Health Workers are key strategies for improving service access and engagement.

Aboriginal people should have choice in their own healthcare and feel safe and confident to access all health services. As well as ensuring mainstream services are better able to meet their needs, Aboriginal-specific services such as Aboriginal Community Controlled Health Services (ACCHSs) that can deliver comprehensive, culturally safe primary care to Aboriginal people, should be part of any strategy for Aboriginal people affected by lymphoedema. Effective partnerships will allow health service providers the opportunity to develop knowledge of Aboriginal culture and associated issues, build trust in the community and support Aboriginal Health Workers in developing clinical skills and protocols in the management of lymphoedema.

People from culturally and linguistically diverse backgrounds

Assessing the needs of people from culturally and linguistically diverse (CALD) backgrounds must consider literacy levels to optimise communication. Clinicians should utilise interpreter services when required and resources should reflect languages other than English. People who have different cultures, languages and religions, who live with or are at risk of lymphoedema, must be treated with respect and recognition of their linguistic, cultural and religious needs. It should also be noted that there can be significant diversity among individuals within their communities.

Rural services

The importance of encouraging, supporting and developing rural services to improve access for people in non-metropolitan areas can be seen by Joan's experience in the following case study. Clearer care pathways, better coordination between services, utilisation of telehealth, and improving local providers' awareness and education about lymphoedema could have improved Joan's care.

Access to services for rural people remains a challenge. In a survey of 194 women across Australia with breast cancer-related lymphoedema, 30% of rural respondents reported no access to a lymphoedema service (the same was true of 20% of the respondents in major cities).¹⁴

People with lymphoedema living outside urban areas may be required to travel considerable distances for assessment, management and treatment of their condition. Clients with significant lymphoedema may be referred to larger centres and, when this is not possible, must self-manage or rely on a partner to assist with managing their condition.

Joan's story – the problem of access to service

Joan, from rural NSW, already had right inguinal lymph node metastases when her vulval carcinoma was discovered, so she required chemotherapy and radiotherapy before her surgery. She attended radiotherapy at a metropolitan cancer service and during this time her leg swelling commenced. Joan was advised lymphoedema was likely. Joan's local rural hospital lymphoedema service only treated breast cancer-related lymphoedema, so Joan tried to find assistance with her swelling during her radiotherapy treatment in the city. However, as she was not a local resident, she was ineligible to receive treatment. Worried, she sought help from alternate health practitioners for massage. Immediately after surgery, Joan's lymphoedema increased and her surgical wound took months to heal. Eventually a local community nurse demonstrated lymphatic massage to Joan's husband and a compression garment was obtained from a supplier.



Three years on, Joan remains distressed and frustrated that she spent substantial time and funds trying to find treatment. Joan's leg and lower abdomen remain swollen; she has not returned to work or gardening, and feels over-dependent on her husband who continues to massage her each day.

Principle 1

Early identification, education and monitoring of patients at risk of lymphoedema

People at risk of lymphoedema have not yet displayed the signs and symptoms of lymphoedema but have a known insufficiency of, or injury to, their lymphatic system. This includes people who have undergone removal of lymph nodes or radiation therapy for cancer treatment.

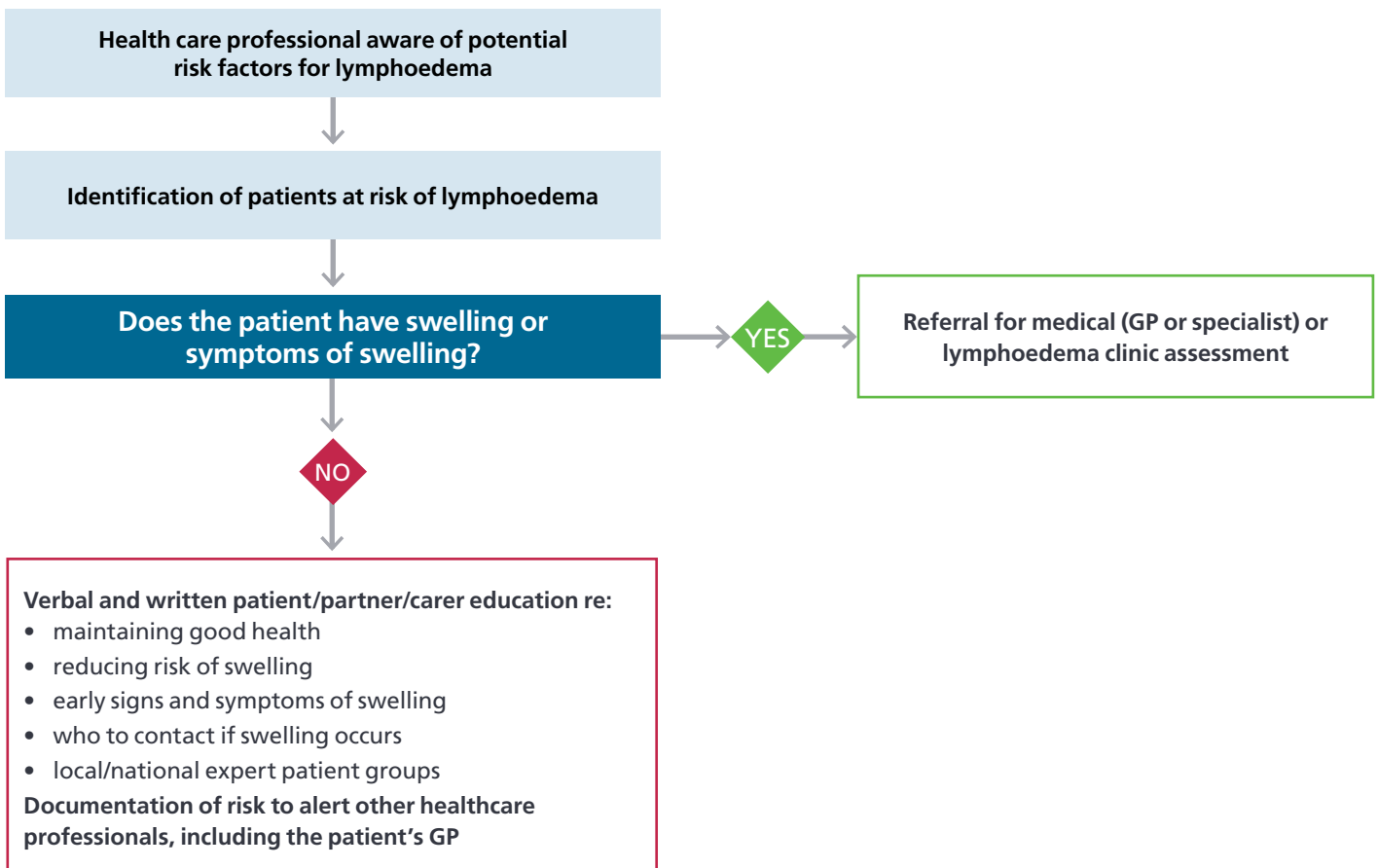
It is not known why some people with the same risk factors develop lymphoedema and others do not. An underlying predisposition to developing lymphoedema may be a contributing factor.²⁶⁻²⁸ Research evidence is limited regarding the specific outcome of current risk reduction practices recommended to reduce the likelihood of developing lymphoedema in at-risk patients.²⁹

According to *Best practice for the management of lymphoedema*, 'Effective identification of patients at risk of lymphoedema relies on awareness of the causes of lymphoedema, associated risk factors, implementation of preventive strategies and self-monitoring.'⁶ The ideal care model for those at risk of lymphoedema is outlined in Figure 1 below.

'It took five different specialists before I was diagnosed with lymphoedema ...'

– Susan¹

Figure 1: Care model for those at risk of lymphoedema



Early identification of those at risk of lymphoedema

Recognising those vulnerable to lymphoedema is an important step in reducing the risk of lymphoedema. Early intervention, in the form of appropriate education as well as self and professional monitoring will facilitate this. Understanding possible causes or triggers for lymphoedema can help non-lymphoedema specialists to identify patients at risk, allowing targeted education and monitoring.

Applying the principle in practice

- All people identified as at risk of developing lymphoedema are provided with relevant information where appropriate as part of their consent to treatment.
- The HETI online lymphoedema awareness training is completed by health service staff.
- Clear care pathways are developed to identify those at risk of lymphoedema.

Education on lymphoedema risk factors and development

Education for people at risk of lymphoedema should be individualised and timely. Education should be ongoing and reinforced along the treatment continuum to ensure that information is retained and there are opportunities to address questions. The individual, carers and health professionals should be aware that there may be a considerable delay from the causative event to the appearance of lymphoedema.⁶ For this reason, patient education about self-monitoring is critical, to ensure their early return for review, should they develop any signs or symptoms.

Applying the principle in practice

Evidence-based education may be made available to patients and carers in a variety of formats, including:

- individual one-on-one sessions
- group education sessions
- online resources – [see page 16](#)
- written materials, ideally including languages other than English for culturally and linguistically diverse (CALD) people
- culturally appropriate education materials for Aboriginal people (consider a learning map, for example)

😊 **Consideration for education of carers and family members.**

😊 **Age-appropriate resources.**

Monitoring for early signs and symptoms of lymphoedema

People who have been identified as at elevated risk of lymphoedema require regular monitoring to enable early detection and treatment of lymphoedema.^{30, 31} As a part of the patient's care plan, routine clinical reviews should include lymphoedema monitoring.

Early identification and management of lymphoedema can result in improved outcomes and may reduce the impact of the condition on the survivor's quality of life.³²⁻³⁴

Care provided to people with lymphoedema can start in the primary care setting. GPs are often responsible for an initial diagnosis, guiding access to specialist services or clinics, coordinating care and supporting the patient's journey. The role of GPs outside urban centres is particularly vital due to difficulties accessing specialist services and clinics. GPs may require support and guidance to effectively manage a person with lymphoedema.

Applying the principle in practice

- Monitoring for the early detection of lymphoedema occurs in those with elevated risk.
- Those identified and educated about their risk should also be informed of their local lymphoedema services.
- Patients identified as benefiting from monitoring should be assessed, including:
 - a subjective history for patient symptoms such as heaviness, tightness, swelling or aching in the at-risk limb or body region
 - physical examination of the limb or body region, including pitting test
 - physical measurements of both limbs using tape measurement and/or bioimpedance spectroscopy are consistently applied.³⁵ These measurements should be compared to normative ranges (and/or against baseline measures for cancer-related lymphoedema).

Table 1: Suggested monitoring of patients at risk³⁶ of lymphoedema

At-risk condition	Recommendation for monitoring
Cancer-related risk of lymphoedema (e.g. breast, melanoma, gynaecological, prostate, sarcoma, head and neck)	<ul style="list-style-type: none"> • Pre-treatment measurements if possible • Review 3-6 monthly for the first 2 years (specialist or clinic and/or GP) • Review if any change develops • Education to facilitate self-monitoring
Cellulitis	<ul style="list-style-type: none"> • Review at resolution of infection • Review 3-6 monthly for 1 year (GP) • Education to facilitate self-monitoring
Venous surgeries (e.g. varicose veins) or venous insufficiency.	<ul style="list-style-type: none"> • Education to facilitate self-monitoring
Deep vein thrombosis (DVT)	<ul style="list-style-type: none"> • Education to facilitate self-monitoring
Hereditary lymphoedema	<ul style="list-style-type: none"> • Review of siblings and progeny regularly or as clinically relevant (specialist or clinic and/or GP) • Genetic counselling as appropriate

Implementation

- Work collaboratively with primary health networks (PHNs), LHDs and SHNs to develop localised health pathways for lymphoedema to assist GPs and Aboriginal Health Services.
- Health professionals undertake the online training developed by HETI to support identification, education and monitoring of patients at risk of lymphoedema.
- LHDs support health professionals to attend Level 1 lymphoedema training.
- Protocols and policies are in place to identify patients at high risk of lymphoedema.
- Preoperative information relating to risk of lymphoedema is provided to patients at high risk.
- Initial and ongoing education is provided to people at risk of lymphoedema.
- Protocols and policies are available for monitoring for the early detection of lymphoedema in high-risk groups.

Maria's story – the importance of education and monitoring

Maria's breast cancer was identified by breast screening. Prior to her mastectomy and axillary lymph node clearance, she was reviewed by her team's physiotherapist. The postoperative risk of lymphoedema was discussed and arm measurements were taken using both tape measure and bioimpedance. Postoperatively in hospital, Maria was reviewed by the physiotherapist, who commenced arm exercises and provided further information about lymphoedema, including using the arm normally, encouraging weight management and exercise. A review plan was discussed with Maria. During her chemotherapy, Maria developed early arm swelling confirmed by measurement as lymphoedema. Further therapy was provided, including a compression sleeve, a review of her exercises and self-massage technique. Maria's arm swelling initially settled but returned during her radiotherapy. A short program of lymphoedema massage, laser



and taping was implemented with a new, stronger compression sleeve prescribed. Over the following 12 months she was reviewed regularly by the team's physiotherapist and her measurements and L-Dex (lymphoedema index) normalised. Maria was encouraged to return to her former recreational activities without her sleeve and continue self-monitoring.

Principle 2

Identification, assessment and diagnosis of lymphoedema by a trained health professional

According to *The diagnosis and treatment of peripheral lymphedema: 2013 consensus document of the International Society of Lymphology*: "An accurate diagnosis is essential to appropriate therapy... In most patients, the diagnosis of lymphoedema can be readily determined from the clinical history and physical examination."³⁷ The diagnosis and assessment of the person possibly developing lymphoedema should be holistic in its approach and encompass the physical, functional or psychosocial issues that a person may be facing. A complete initial assessment should include: taking a history, conducting a physical examination and arranging or interpreting diagnostic tests to confirm lymphoedema is the cause of the swelling. The objective measurement of the region with lymphoedema is an essential component and determinant of any treatment regime and in documenting outcome.⁶

'At age 58 I was diagnosed with lymphoedema after having treatment for breast cancer. My physiotherapist diagnosed my condition and has been looking after me since. She is a trained lymphoedema specialist physiotherapist and has been great.'

– Judy¹

Timely identification of lymphoedema

In many cases treatment of lymphoedema is most effective when lymphoedema is diagnosed at the earliest stage.³⁸

Lymphoedema can present with multiple contributing factors that can delay timely diagnosis. In some cases, for example following cancer treatment where vulnerability to the development of lymphoedema is known or anticipated, it can present in a range of ways. Symptoms may include heaviness, tightness, swelling or aching in the at-risk limb. Any symptoms should be investigated and assessed for diagnosis as early as possible to reduce morbidity. Other presentations, such as primary lymphoedema, can appear unexpectedly at any stage in life.

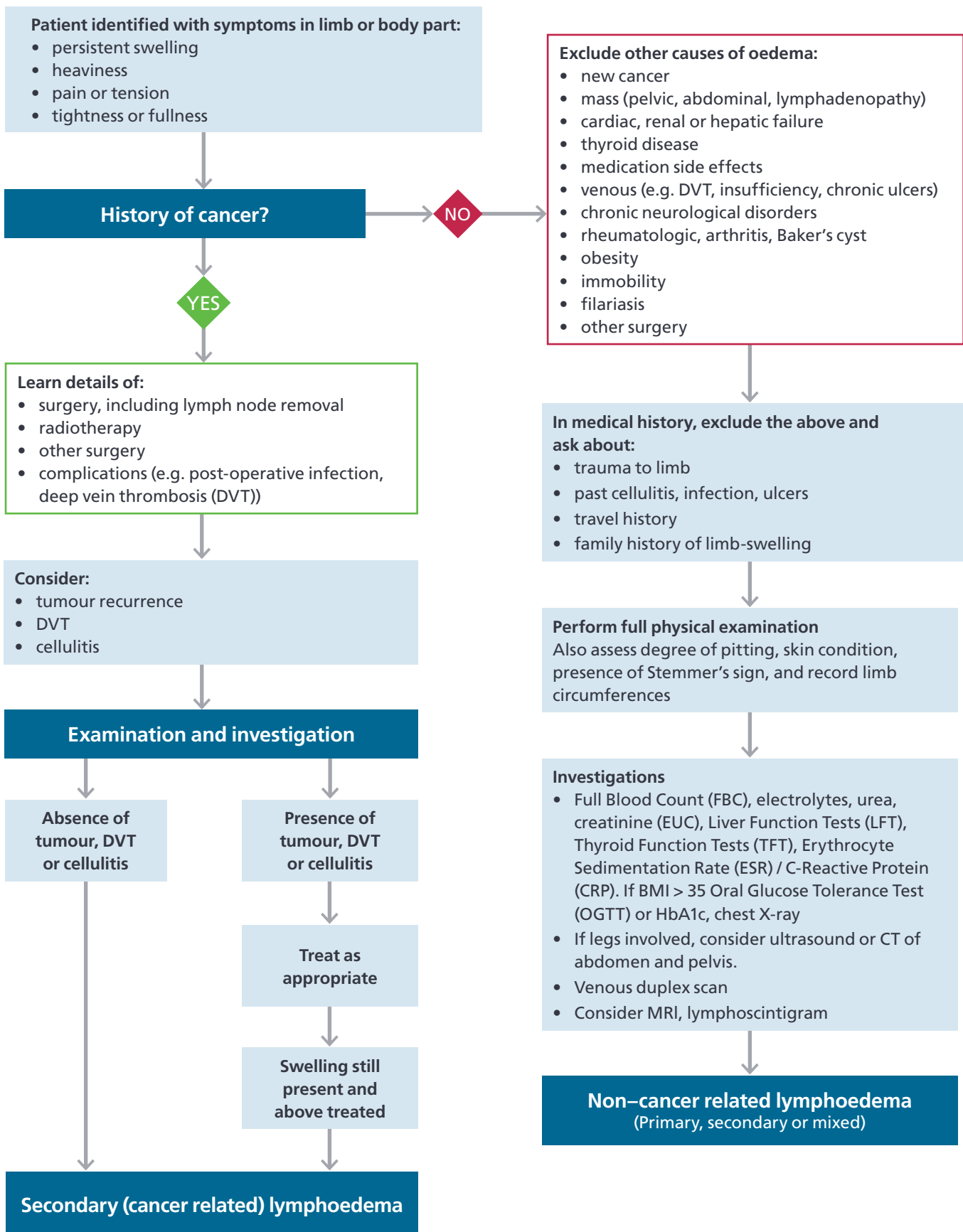
Applying the principle in practice

- Clinicians working in the health care services listed below should be aware of the early signs of lymphoedema and the importance of early intervention. See [Figure 2 on page 11](#) for a diagnosis algorithm.
- A patient with swelling should be encouraged to seek clinical assessment and treatment as soon as possible.
- All presentations should be treated as though they are chronic. Occasionally swelling may be transient and related to treatment (for example Taxane-based therapy) but those people whose lymphoedema will be transient may not always be readily identified.

Health care services where lymphoedema might be identified

- | | |
|--|--|
| <ul style="list-style-type: none">• Cancer care clinics (including radio-oncology services)• Leg ulcer clinics• Vascular clinics• Diabetes clinics• Dermatology clinics• Burns clinics• Palliative care services• General practice• Hospital in the Home, particularly post-cellulitis | <ul style="list-style-type: none">• Residential aged care facilities• Orthopaedic postoperative clinics, particularly physiotherapy departments• Paediatric services• Physiotherapy and occupational therapy services• Podiatry services• Disability/rehabilitation services• Home care services• Emergency departments |
|--|--|

Figure 2: Lymphoedema diagnosis (modified from *Lymphoedema: Guide for diagnosis and management in general practice*³⁹)



Comprehensive clinical assessment by an appropriately trained health professional

People identified with symptoms or signs of lymphoedema should receive a timely clinical assessment by an appropriately trained health professional: a medical practitioner or an accredited lymphoedema practitioner (such as a registered nurse, physiotherapist or occupational therapist) who has completed an accredited lymphoedema training course.⁴⁰

Assessment may include the following:

- Medical and psychosocial history, including history of cellulitis
- Clinical assessment, including review of medical history and physical examination (skin condition, including pitting and fibrosis, location of swelling, joint range of motion and strength, mobility, body mass index (BMI), ankle-brachial pressure index (ABPI). Clinical assessment should include determination of the ISL stage – see Table 2 to the right.
- Measurement of the limb or region with swelling: circumference, volume and/or bioimpedance spectroscopy
 - Additional guidance on circumference measurements can be found in the Australasian Lymphology Association (ALA) position statement and measuring guide⁴¹: www.lymphoedema.org.au/about-lymphoedema/standards-guidelines

An Allied Health Lymphoedema Assessment proforma can be located on the NSW electronic medical record (eMR) system.

Table 2: International Society of Lymphology (ISL) lymphoedema staging³⁷

Stage 0	A subclinical state where swelling is not evident despite impaired lymph transport. This stage may exist for months or years before oedema becomes evident.
Stage I	This represents early onset of the condition, where there is accumulation of tissue fluid that subsides with limb elevation. The oedema may be pitting at this stage.
Stage II	Limb elevation alone rarely reduces swelling and pitting is manifest.
Late Stage II	There may or may not be pitting as tissue fibrosis is more evident.
Stage III	The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyper pigmentation, increased skin folds, fat deposits and warty overgrowths develop.

Applying the principle in practice

- Comprehensive clinical assessment is provided to patients by a GP or an appropriately trained lymphoedema practitioner within four weeks of the identification of their symptoms, or as appropriate to their clinical need.
- ☺ **Individualised planning for young people with lymphoedema should be considered when involving an appropriately trained health professional⁴² (e.g. new patients presenting <16 years old can continue in a paediatric service until they turn 18, while those presenting >16 attend an adult service.)**

Marilyn's story – appropriate monitoring and diagnosis

Marilyn was 46 years old when she was diagnosed with lymphoedema. Her symptoms appeared after a radical hysterectomy for cervical cancer. The surgeon did explain that surgery could result in lymphoedema and at each check-up Marilyn was examined for evidence of lymphoedema. Six months after surgery and following an extended car trip, Marilyn experienced swelling in her legs. Her surgeon examined her swelling and recommended an ultrasound of the veins in Marilyn's leg to rule out other causes for the swelling. Therapists at a private hospital confirmed Marilyn's lymphoedema.



Clinical diagnosis by an appropriately trained health professional

Most cases of lymphoedema are diagnosed based on medical history and physical examination. If alternative diagnosis of swelling is suspected, involvement of appropriate medical professionals may be needed to facilitate the required investigations. The choice of investigations used to determine the cause of the swelling will depend on the history, presentation and examination of the patient. Lymphoedema can be a diagnosis of exclusion, made by ruling out other causes. The differentials shown below need to be taken into consideration and investigations ordered as appropriate.

RED FLAGS for diagnostic review

- Sudden acute onset
- Pain as a principal complaint
- Skin colour changes
- Collateral vein visible
- Lumps, sores, ulcers
- Paraesthesia, other neurological signs
- History of cancer, unmonitored



Medical review and investigation to exclude other causes of swelling or presentation.

Differential diagnosis of lymphoedema⁶

Unilateral swelling

- Acute deep vein thrombosis
- Post-thrombotic syndrome
- Arthritis
- Baker's cyst
- Post treatment
- Presence/recurrence of carcinoma*

Symmetrical swelling

- Congestive heart failure
- Chronic venous insufficiency
- Dependency or stasis oedema
- Obesity
- Renal dysfunction
- Hypothyroidism/myxoedema
- Drug induced (e.g. calcium channel blockers)
- Lipoedema
- Filariasis
- Fluid retention syndromes

N.B. These conditions may coexist with or cause lymphoedema. Some of these conditions are relevant to upper and/or lower limbs.

* Presence or recurrence of carcinoma requires direct referral to the appropriate oncology service.

Specialised tests are available for lymphoedema if required. These include:

- Lymphoscintigraphy – a nuclear medicine procedure used to demonstrate lymphatic morphology, particularly where the cause of the swelling is unclear.
- Indocyanine green fluoroscopy – to identify superficial lymph channels and to evaluate potential candidates for microsurgery or to advise on lymphatic drainage direction.
- Ultrasound – to identify skin thickness, oedema and tissue fibrosis.

Applying the principle in practice

- Appropriately trained health professionals, specialist or GP are available to clinically diagnose lymphoedema.
- Appropriate specialised tests will be used to assist with the diagnosis of lymphoedema.

Implementation

- Protocols and policies are in place to ensure that people with lymphoedema are identified within three months of lymphoedema indicators.
- Appropriately trained health professionals are available to complete a comprehensive assessment and clinically diagnose lymphoedema.



IDA'S STORY – A PAEDIATRIC CASE

When Ida was 14 months old, her paediatrician noticed her leg was swollen. Ida and her parents saw Jenny, a non-lymphoedema specialist hospital physiotherapist, who provided information, support and simple treatment advice to her parents until she was able to be seen at the Children's Hospital Lymphoedema Service. There, Ida had specialist treatment, compression garments and a commitment to ongoing regular monitoring for her next 16 years. Jenny will be supported to remain part of Ida's care team with her parents and family in her country town.



Principle 3

Patient-centred education to enable self-management of lymphoedema

Self-management support through a partnership between the person and their care provider(s) prepares, supports and ultimately empowers the person to manage their health and ongoing care. Giving people knowledge and confidence to manage their condition is more likely to alter their behaviour and there is good evidence that improved self-efficacy is associated with better clinical outcomes.⁴³

The provision of patient-centred, evidence-based education for patients with lymphoedema can help them with self-management. Education may be provided as one of the components of complex lymphoedema therapy (CLT) and delivered by a trained lymphoedema practitioner. It may also be delivered by other trained health professionals who have completed the HETI online early intervention training. Support groups can also help patients.

'My advice would be to keep up the massage, the exercises and wear the stockings when they are prescribed. Also see a good therapist who specialises in complex therapy for lymphoedema.'

– Ruth¹

Applying the principle in practice

Education is provided in an ongoing manner and tailored to the individual's presentation and needs, emphasising the importance of:

- detecting and reporting changes in the size or feel of the area affected by lymphoedema
- maintenance of healthy body weight
- regular exercise
- adherence to compression therapy, including garments
- maintenance of good skin care
- elevation of an affected limb
- self-massage techniques where appropriate
- awareness of early signs of cellulitis
- protection against injury.



PAEDIATRIC CONSIDERATIONS

For paediatric patients, education of the patient as well as the parents/carers and siblings should be included in basic management. This education must be age-appropriate and consider the patient's understanding, capacity to self-manage and adherence levels where capable. Other community carers (e.g. school, sports coaches) may need education about lymphoedema and its management.

Resources to assist with education of patients and health care professionals

The following resources can be used to facilitate patient self-management.

Patient education resources (evidence-based)

- **Lymphoedema – What you need to know** canceraustralia.gov.au/sites/default/files/publications/lnc-lymphoedema-what-you-need-to-know_504af02fe04d6.pdf (Cancer Australia, 2013)
 - **Lymphoedema: Westmead Breast Cancer Institute (Western Sydney Local Health District)** www.bci.org.au/breast-cancer-information/fact-sheets/lymphoedema/ (Westmead Breast Cancer Institute, Version 4, May 2012)
 - **Lymphoedema Fact Sheet** www.bcna.org.au/media/2141/bcna-lymphoedema-fact-sheet.pdf (Breast Cancer Network Australia, July 2016)
 - **National Lymphoedema Network’s (NLN) Position Statement on Risk Reduction Practices for those at risk of and living with lymphoedema (2012).** www.lymphnet.org/pdfDocs/nlnriskreduction.pdf
 - **The Australasian Lymphology Association**
Audio-visual: ALA ‘Survive and thrive’ videos
www.lymphoedema.org.au/education-&-resources/promotions/
- ☺ *The big book of lymphoedema* – available on Amazon and similar websites.

Allied health practitioner training (HETI)

The two online modules *Lymphoedema awareness* and *Lymphoedema early intervention* available on HETI’s ‘My Health Learning’ platform include two resources to specifically assist allied health professionals.

- Overview of lymphoedema, oedema and cellulitis www.heti.nsw.gov.au/Global/allied-health/Lymphoedema/Lymphoedema-Awareness-Quick-Reference-for-Therapists.pdf
- Self-management techniques www.heti.nsw.gov.au/Global/allied-health/Lymphoedema/Lymphoedema-Intervention-Techniques.pdf

Implementation

- Patient-centred education is available.
- Appropriately trained health professionals are available to provide patient-centred education to people with lymphoedema.
- Provide improved opportunities for targeted training and education of health practitioners to increase awareness and understanding of lymphoedema.

Comprehensive treatment tailored to patient needs and clinical reasoning

Patients with lymphoedema should have a coordinated treatment plan and be provided with information appropriate to their needs. Early, active involvement of the patient and/or carers is important. The management of lymphoedema may vary according to the acuity of the condition, so treatment should be responsive to patient needs over time. Often initial treatment plans will focus on a period of more active and regular treatment aimed at reducing the area of swelling. Once the reduction is achieved, a different (maintenance) approach to treatment may be considered. The development of a treatment plan should be undertaken by an accredited lymphoedema practitioner.

'Over a period of five weeks, I was hospitalised to reduce leg swelling. This was followed by compression garments (50mm Hg). Since that time, I wear them daily along with carrying out a light massage.'

– Grahame¹

Selection of appropriate treatments

There are many treatment modalities that may be utilised independently or in combination with other treatments to manage lymphoedema. For many of these modalities, treatments are based on best-practice guidelines and experience rather than a substantial body of evidence, particularly for some presentations of lymphoedema.

Treatments used for people with lymphoedema include:

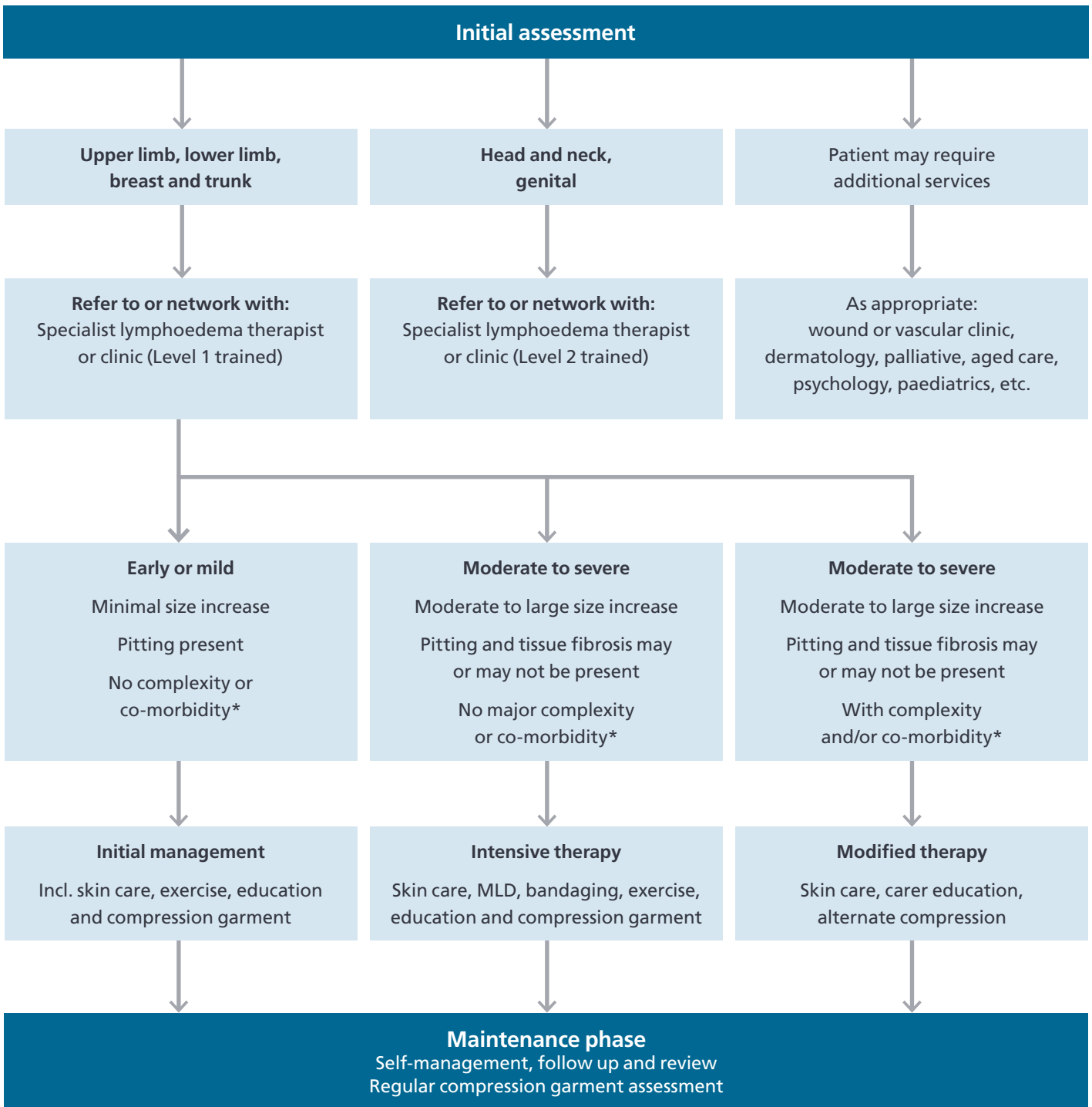
- Skin care
- Manual lymphatic drainage (MLD) decongestive massage
- Multilayer bandaging
- Traditional compression garments
- Other compression methods
- Pain management
- Exercise
- Weight management
- Psychosocial management
- Education regarding self-management techniques.

In addition, there are several adjunct treatments that may be appropriate. These may include:

- Low level laser therapy (LLLT)
- Sequential intermittent pneumatic compression (SIPC)
- Lymph taping
- Surgery.

Concurrent therapies include pain and wound management. See [Appendix 2: Lymphoedema treatment description and applications](#). An overview of treatment options for different areas of lymphoedema is provided over page in [Figure 3](#).

Figure 3: Lymphoedema treatment (modified from⁶⁾)



*Complexity and co-morbidity can include: fragile skin, skin ulceration, significant shape distortion, unable to tolerate or apply or remove compression garment, palliative treatment.



PAEDIATRIC CONSIDERATIONS

There is very limited evidence regarding treatment techniques in paediatric lymphoedema. An experienced paediatric therapist should consider the above treatment options and make necessary and appropriate modifications considering the age, size, growth, understanding, and requisite monitoring of their patient.^{42, 44}

Applying the principle in practice

- Every patient diagnosed with lymphoedema will have a comprehensive management plan determined by the site, stage, severity and complexity of the lymphoedema and the patient's psychosocial situation.
- Patients with head, neck or genital lymphoedema will have access to a specialist lymphoedema therapist or clinic (Level 2 trained).
- Patients with upper limb, lower limb, breast or trunk lymphoedema will be identified (as per [Figure 3](#)) and have treatment plans that incorporate:
 - Initial management, including skin care, exercise, education and recommended compression garment

- Intensive therapy: skin care, MLD, bandaging, exercise, education and compression garment
- Modified therapy: skin care, carer education, alternate compression methods.

- Patients in the maintenance phase should have education and support, to encourage self-management, with regular follow up and review, including compression garment assessment.
- Treatment plans are evidence-based and tailored to patient needs and the clinical reasoning of the health practitioner.
- Budget for lymphoedema treatment includes, as well as staffing, equipment for assessment and treatment, and consumables.

Due to the chronic nature of lymphoedema, there is a variety of treatment modalities from which clinicians may choose. These treatments are outlined in [Appendix 2](#).

- ☺ **Patients less than 16 years old have access to a specialist paediatric lymphoedema therapist at a tertiary hospital or an appropriately trained lymphoedema practitioner.**⁴²

Haasim's story – the importance of awareness in primary care

After a car accident resulting in multiple fractures, Haasim was advised by his GP to monitor his lower limbs for swelling. This was also routinely checked by his GP. Several months after his accident, Haasim experienced right leg swelling and consulted his GP. The GP excluded other causes such as DVT and malignancy, then referred Haasim to the hospital lymphoedema service.

He was seen quickly and assessed by the lymphoedema practitioner to have early (stage 1) lymphoedema. Haasim was then provided with education, shown self-management techniques and measured for a compression garment. He was encouraged to exercise regularly and maintain a healthy weight range.

He is seen and monitored regularly, with replacement compression garments being organised through Enable NSW.



Principle 5

Correct provision of compression garments according to clinical recommendations

All patients with a new clinical diagnosis of lymphoedema should be assessed for, and initially prescribed, a minimum of two full sets of compression garments by a suitably qualified health professional. This is to ensure optimum therapeutic outcome is maintained.⁶

A compression garment is a clinically prescribed compression device which provides appropriate graduated compression to a lymphoedematous limb (including both custom-made and ready-to-wear compression garments, and wrap products).

The role of compression garments in treating lymphoedema extends from early intervention to long-term management. The use of compression garments to maintain the gains made by intensive treatment is multifactorial and depends on the appropriate choice of garments and the adherence of the person in wearing them.⁴⁵

The average cost of custom-made garments for a typical lower leg cellulitis/lymphoedema patient is \$900 for two sets, a significant cost for many people living with lymphoedema.

Yet this cost is much smaller than the cost of a hospital admission. According to the NSW Activity Based Management (ABM) portal, in 2015-16 the cost of admission to a NSW public hospital for a patient with cellulitis as the primary diagnosis and lymphoedema as a secondary diagnosis was \$6193 per admission, with an average length of stay of 5.53 days. The average cost of two sets of custom-made compression garments for a typical lower limb lymphoedema patient is only about 14 per cent of the total cost of an admission to hospital. There is a benefit to the health system with the cost of compression garments being less than unnecessary admissions.

'It's essential that you are professionally assessed for your [compression garments] as the wrong garment causes a lot of problems.'

– Lila¹

Applying the principle in practice

- Prescription of compression garments is carried out by a Level 1 trained health care professional.
- All forms of lymphoedema are considered for garment prescription.
- All patients are educated about appropriate garment review and replacement options.
- Compression garments are replaced every six months or according to manufacturers' standards or clinical recommendations.⁶
- Patients are informed of appropriate long-term garment funding options, which may include Enable NSW, NDIS or other government-established support services.
- Palliative patients are provided with appropriate compression garments using health professionals' clinical reasoning and considering patient needs.

☺ **Paediatric patients are provided with compression garments based on health professionals' clinical reasoning and patient needs.**



PAEDIATRIC CONSIDERATIONS

Paediatric patients may require garment replacement more often than every six months; the timing of garments for paediatric patients will depend on growth rates and wear and tear. At a minimum this will be as per the manufacturer's standards (every 3-6 months depending on fabric) but may well be more frequent. Paediatric patients are generally issued with two sets of garments, however sometimes more sets are issued, for example when children are toilet training. Clinical reasoning and social considerations will determine decisions in this area. Paediatric patients are assessed in a speciality clinic and garments are funded for these patients until the age of 18.

Implementation

- Level 1 trained health professionals prescribe compression garments for all people with lymphoedema.
- Patients receive education about garment care, replacement and funding.

Identification of contraindications to compression therapy

Compression of peripheral oedema may not always be appropriate. Contraindications for compression are important to consider and include: severe arterial insufficiency, uncontrolled heart failure, or severe peripheral neuropathy. Prior to commencing lower leg compression, vascular assessment is recommended to rule out any underlying arterial insufficiency.⁴⁶ ABPI is considered more reliable than palpation of pulses. Caution is advised in people with high blood pressure, cardiac arrhythmia or cardiac stenosis, controlled heart failure, scleroderma, sensory deficits, diabetes mellitus, low platelet count and those undergoing chemotherapy.

- ☺ **Caution should be taken with using compression on children with growing skeletons.**
- ☺ **Extreme caution is advised for lymph taping in people less than eight years old and in other patients with fragile skin.**

Applying the principle in practice

- When needed, the ABPI should be performed by a trained health professional. An ABPI below 0.8 (current vascular guidelines now suggest 0.5 may be acceptable in some patients⁴⁷) or above 1.2 may indicate that compression is not appropriate and requires further testing.
 - People wearing compression garments should be taught to monitor limbs for signs of ischaemia including change in sensation, colour and pain, and skin injury.
 - Medical advice from a GP, clinic or specialist should be sought if the assessment indicates that there is a condition which is contraindicated or where caution arises for compression.
- ☺ **Appropriate methods to identify that a garment is getting too small and therefore applying incorrect compression should be taught to any patient/carer where rapid growth is anticipated (e.g. paediatrics, pregnancy).**

Implementation

- People with lymphoedema have a treatment plan and information appropriate to their specific needs.
- Appropriately trained health professionals develop and deliver appropriate treatment plans for people with lymphoedema.
- Appropriately trained health professionals perform ABPI when required.

Principle 6

Effective management of lymphoedema-associated cellulitis, including prevention of recurrence

People with lymphoedema experience a significantly heightened risk of cellulitis in the affected body area. Cellulitis is caused by spreading bacterial inflammation of the skin, resulting in redness, pain, and lymphangitis. Cellulitis can result in systemic illness and or local necrosis and abscess formation. Treatment will require antibiotic management and is the most common cause for hospitalisation for people with lymphoedema. The treatment of cellulitis in lymphoedema may differ from conventional cellulitis.^{5, 39} Cellulitis of the legs can be confused with stasis dermatitis. A failure to respond to antibiotic therapy requires specialist consultation to clarify diagnosis.

Non-purulent cellulitis is most likely caused by *Streptococcus A* or *G*, which remains 100% sensitive to penicillin.³⁷ Purulent cellulitis is more likely caused by *Staphylococcus aureus*, which has a significant resistance profile.^{37, 42}

Cellulitis is both a risk factor for lymphoedema development and for lymphoedema deterioration.⁴⁸ Cellulitis can lead to obstruction and damage of the lymphatic system, which predisposes people to recurrent cellulitis.¹⁰ Effective conservative management of lymphoedema has been shown to significantly reduce the frequency of cellulitis.^{37, 43}

According to the NSW ABM Portal, in 2015-16 admissions for cellulitis (primary and secondary diagnoses) cost just under \$125 million. NSW Health data identifies cellulitis as the most potentially preventable hospitalisation.¹¹

In the context of lymphoedema management, all people:

- presenting with cellulitis should be assessed for an underlying lymphatic condition
- with lymphoedema should be provided with information about cellulitis and its treatment
- with lymphoedema, associated cellulitis and recurrent cellulitis should be managed using evidence-supported protocols
- with lymphoedema-associated cellulitis should be referred for lymphoedema therapy to reduce recurrence.

'I have always caught my cellulitis early since the first outbreak. I now limit what I do to avoid skin damage... and have not been hospitalised. I recently took an over-the-weekend antibiotic as I felt a problem coming on... my GP agreed that the condition looked suspicious and an outbreak was averted'

– Judy¹

Applying the principle in practice

- The treatment of a person admitted with cellulitis should include:
 - treatment of infection
 - assessment for possible underlying lymphatic dysfunction.
- All people with lymphoedema should have access to cellulitis education, including:
 - skin care, particularly identification and treatment of fungal infection in feet
 - self-management of skin trauma
 - need for podiatry for lymphoedema-affected feet
 - self-identification of early signs and symptoms of cellulitis
 - antibiotic management plan.
- Information should be made available to GPs, emergency department (ED) staff, allied health and nursing staff about the high risk of cellulitis in the affected body part for patients with lymphoedema. Information should emphasise the need for early intervention and a proactive plan to ensure timely antibiotic management.
- People with lymphoedema who present with cellulitis in the affected area should be managed according to best practice protocol.
- All patients with established lymphoedema presenting with cellulitis should be referred to a specialist lymphoedema service.

Table 3: National and international consensus documents for the management of cellulitis in lymphoedema

Resource	Address
ALA consensus document	www.lymphoedema.org.au www.lymphoedema.org.au/about-lymphoedema/consensus-guideline/
British Lymphology Society (BLS) consensus document	www.thebls.com

Implementation

- All patients presenting with cellulitis are assessed for subclinical or overt lymphoedema.
- All patients with lymphoedema should be provided with information about cellulitis and its treatment.
- Protocols and policies are in place to ensure that patients with lymphoedema cellulitis are diagnosed and managed using evidence-based protocols and are referred for lymphoedema therapy.

Bob's Story – a problem of delayed diagnosis

Bob was diagnosed with prostate cancer in 2001. He underwent surgery to remove several inguinal nodes, followed by radiation therapy. He remains cancer-free after 15 years, but six months post-treatment, Bob's right leg began to swell. His family doctor advised him to monitor it and return to him in six months if the swelling continued. During the next six months, the swelling progressed, and Bob developed lymphorrhea. Sanitary pads were used, taped to his leg to 'mop up' the leakage.

A Doppler scan and a referral to a vascular specialist were organised. No vascular disorder was identified, and skin care was then managed locally for the next three years, with absorbent padding and leg elevation recommended.

Bob adhered to this method of treatment for three years, during which time he suffered four episodes of cellulitis and subsequent multiple antibiotic treatments; he also gained 32kg. During his fourth hospital admission for cellulitis, the underlying issue of lymphoedema was identified.



Bob was referred to a dermatologist and a lymphoedema therapist, who worked together to manage Bob's wounds and reduce limb volume with a combination of MLD, bandaging and prescription exercises. It took eight weeks to reduce the volume of Bob's leg, and then he was fitted with prescription-strength compression garments. Bob is now regularly reviewed by the lymphoedema therapist for effective compression garments and skin care monitoring. He has had no cellulitis episodes or related hospital admissions for the last three years.

Principle 7

Effective response to inpatients

People with lymphoedema who present or are admitted to NSW health facilities should be assessed by suitably trained and skilled health care professionals. Lymphoedema is often a secondary diagnosis and its significance is not adequately recognised. After assessment, appropriate interventions should be arranged. These interventions may include ward-based care and/or liaising with appropriately trained specialist clinicians identified in their LHD/SHN. Effective hospital-based management of patients with cellulitis, lymphorrhea or both can reduce delays in discharge and also rates of re-presentation to NSW health care facilities.^{49, 50}



CATHERINE'S STORY

Catherine had been attending a tertiary children's hospital for management of her primary bilateral lower limb and trunk lymphoedema since she was six months old. At age 12, her mother noticed that she appeared to have scoliosis, so the lymphoedema service organised for an orthopaedic review. Catherine proved to have a rapidly progressing curve, so she was immediately referred to orthotics for spinal bracing.

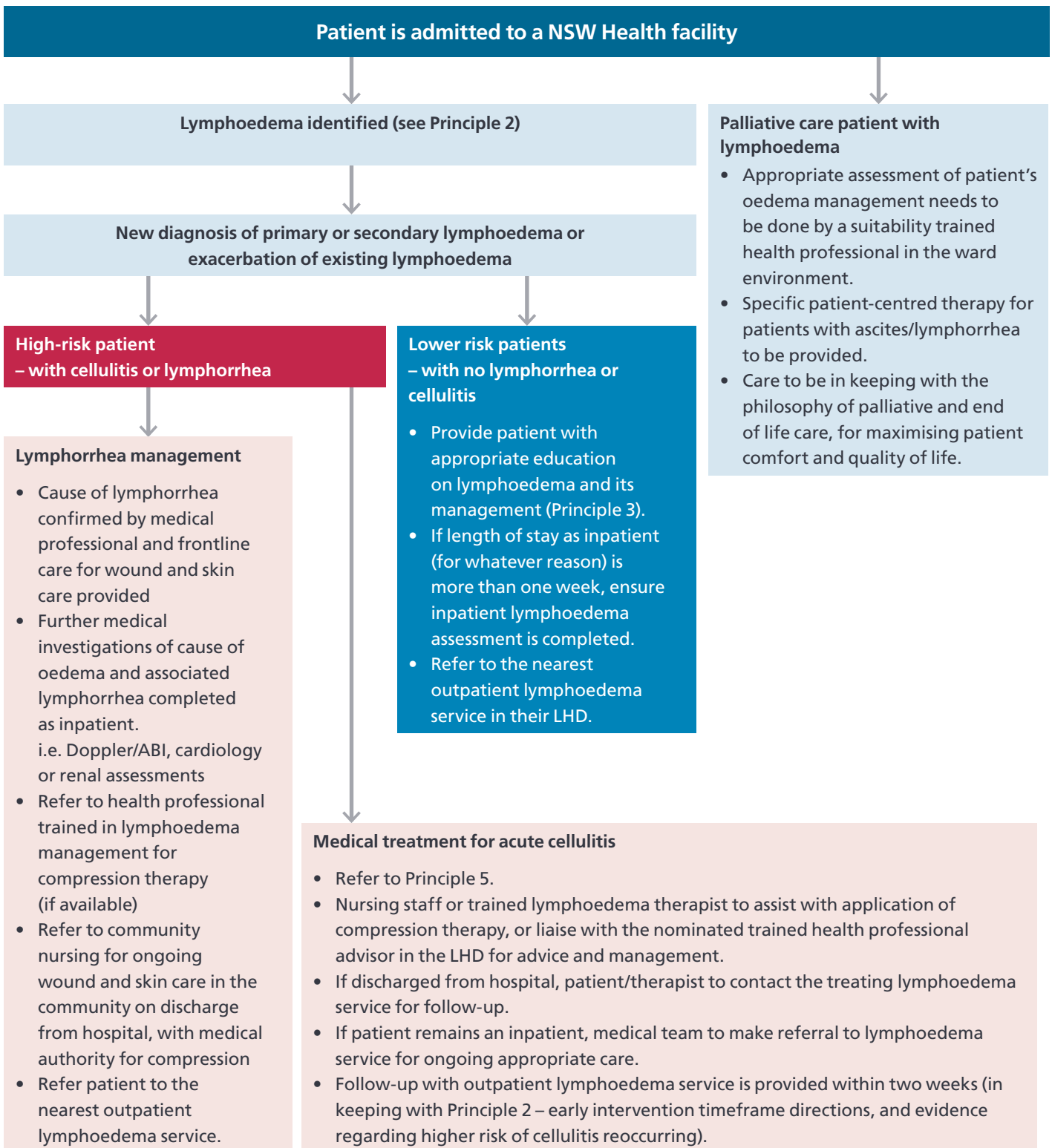
Her lymphoedema was considered at all stages during her bracing trial, with custom minimal-contact bracing to optimise lymph flow, and modifications to her compression garments to allow for the brace. Bracing was effective only short-term, and Catherine needed to be admitted for spinal fusion to halt the progression of her scoliosis. The surgical approach was discussed at length with the lymphoedema clinicians to minimise impact on her management, and to protect and preserve her functioning lymph channels.



Postoperatively, Catherine was managed by the ward staff in consultation with the lymphoedema physiotherapist to optimally control her oedema as she recommenced mobilising.

Applying the principle in practice

Figure 4: Care pathways for newly identified patients with lymphoedema may include, but are not restricted to, the following:



Implementation

- Suitably trained and skilled health care professionals with a minimum of Level 1 training will provide appropriate interventions to patients admitted or presenting with lymphoedema to NSW health facilities.

Conclusion

Optimal management of lymphoedema requires early identification by appropriately qualified clinicians. Effective, evidence-based treatment can prevent progression to a permanent, irreversible state and reduce the risk of cellulitis. The adoption of the principles of care outlined in this document will guide LHDs and clinicians to build effective services that will greatly enhance health outcomes for people at risk or living with lymphoedema in NSW.



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Other resources

Organisations

Australasian Lymphology Association

Professional organisation promoting best practice in lymphoedema management, research and education in Australasia.

www.lymphoedema.org.au

British Lymphology Society (BLS)

A British charity whose aim is to advance education and knowledge in the field of lymphology and related subjects.

www.thebls.com

International Lymphoedema Framework (ILF)

A dedicated platform for the lymphoedema community to improve the management of the condition and related disorders worldwide.

www.lympho.org

International Society of Lymphology (ISL)

Professional association whose aims include supporting activities which propose to:

- advance and disseminate knowledge in the field of lymphology and allied topics; stimulate and strengthen experimental and clinical investigation; establish relations between basic researchers and clinicians working in the field of lymphology.

www.u.arizona.edu/~witte/ISL.htm

Lymphology Association of North America (LANA)

A non-profit corporation whose objectives are to promote standards for the certification of healthcare professionals who help individuals with lymphoedema and/or related disorders manage their lymphoedema and to promote lymphoedema awareness and the science of lymphology.

www.clt-lana.org

Lymphoedema Education and Research Network

LE&RN is committed to educating the public about lymphatic disease and the need for treatment and research.

lymphaticnetwork.org/

Documents

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Appendix 1: Comparative guidelines/accepted practice protocols

The International Lymphoedema Framework (ILF) published the International Consensus document *Best practice for the management of lymphoedema* in 2006. This continues to be the most widely accepted practice document in the international lymphoedema community. It is publicly available on the ILF website: www.lympho.org

STANDARDS OF PRACTICE FOR LYMPHOEDEMA SERVICES EXTRACT FROM: *BEST PRACTICE FOR THE MANAGEMENT OF LYMPHOEDEMA*. INTERNATIONAL LYMPHOEDEMA FRAMEWORK. 2006, BOX 1, P. 2.

Standard 1: Identification of people at risk of or with lymphoedema

Systems to identify people at risk of or with lymphoedema, regardless of cause, will be implemented and monitored to ensure that patients receive high quality education and lifelong care.

Standard 2: Empowerment of people at risk of or with lymphoedema

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

Standard 3: Provision of lymphoedema services that deliver high quality clinical care that is subject to continuous improvement and integrates community, hospital and hospice-based services

All people at risk of or with lymphoedema will have access to trained healthcare professionals, including lymphoedema specialists, who will work to agreed standards for comprehensive ongoing assessment, planning, education, advice, treatment and monitoring. Care will be of a high standard and subject to continuous quality improvement.

Standard 4: Provision of high quality clinical care for people with cellulitis/erysipelas

Agreed protocols for the rapid and effective treatment of cellulitis/erysipelas, including prevention of recurrent episodes, will be implemented and monitored by healthcare professionals who have completed recognised training in this subject.

Standard 5: Provision of compression garments for people with lymphoedema

Agreed protocols for assessment for and the provision of compression garments for people with lymphoedema, or where warranted, those at risk of lymphoedema, will be implemented and monitored.

Standard 6: Provision of multiagency health and social care

Following comprehensive assessment, any patient at risk of or with lymphoedema who requires multiagency support will have access to and receive care appropriate to their needs from health and social services.

Appendix 2: Lymphoedema treatment description and applications

Treatment	Description	Application/Uses
Education	Promoting self-management by educating patients about their condition and supporting them to learn self-management techniques.	Lymphoedema resources may include a range of verbal, written and audio-visual resources to help promote self-management.
Skin care	Maintenance of skin integrity to provide a barrier and encourage lymphatic flow.	Cleaning and moisturising skin, use of non-perfumed moisturising lotion, protection of skin and early identification and treatment of skin infection. Wound care.
Manual Lymphatic Drainage (MLD) Decongestive Massage	MLD is a gentle, rhythmical massage technique. It aims to encourage fluid away from congested areas by increasing activity of normal lymphatics and bypassing ineffective or damaged lymph vessels.	MLD can be performed by patients or their carers, as educated by clinicians. MLD performed by trained therapists can be used in treatment and maintenance phases, dependent on clinical reasoning. Modified MLD may be appropriate in palliative care too.
Multilayer bandaging	Application of multilayer short stretch bandages with padding in areas of particular concern to ensure graduated compression from the distal to proximal limb.	Clinical reasoning and patient presentation will determine the frequency and duration of bandaging (e.g. type of bandage, patient limitations, oedema reduction). Bandaging may be used intermittently or during exacerbation as part of long-term management, directed by the therapist, dependent on need.
Traditional compression garments	Compression garments are used to maintain limb size. Compression garments can include custom-made or off-the-shelf garments and circular or flat knit. They come in varying levels of compression	Compression garments should be prescribed by a trained lymphoedema practitioner according to clinical reasoning, taking into consideration: <ul style="list-style-type: none"> • patient tolerance (comfort) • patient's ability to put on and take off • location of swelling • severity of lymphoedema • compression (mmHg) level required.
Other compression methods	Non-traditional garments may include things like wraps or have additional features added to the garment, such as zippers and padding.	Traditional compression garments may not be appropriate for some patients or at some times. Other compression methods may be used instead of or in conjunction with traditional garments (low stretch self-adhesive bandaging products/ systems).
Exercise	Various forms of exercise may be prescribed, including gentle range-of-motion and breathing exercises. Other forms of exercise, such as strengthening, may be beneficial in prevention and management.	Exercise programs may be: <ul style="list-style-type: none"> • used in acute phase while in multilayer bandaging • part of long-term self-management • used to assist in weight management and general health [51].
Weight management	Maintenance of BMI in healthy range may reduce risk and severity of lymphoedema.	Options include: <ul style="list-style-type: none"> • education and information • referral to dietician if appropriate.

Treatment	Description	Application/Uses
Psychosocial management	Assist in adjustment of and adherence to treatment and compliance.	<ul style="list-style-type: none"> • Support to adjust to disability • Carer support • Referral to psychological support and programs.
Low Level Laser Therapy (LLLT)	Low output lasers are in the visible to infrared range of wavelength (670-950nm). A wavelength of 904nm is recommended for lymphoedema. ⁵²	Can assist in management of fibrosis, cording, scarring, lymphatic flow and pain management. Used as an adjunct to compression therapy. May also be used as a home therapy option.
Sequential Intermittent Pneumatic Compression (SIPC)	Device providing external pressure to limbs to promote circulation of blood and lymphatics.	Particularly useful for vascular lymphoedema. ⁵¹ For clinical and home use only after pressure prescription and appropriate training with therapist.
Lymph taping	Application of kinesiology tape to facilitate improved lymphatic drainage.	Useful in locations where compression is unable to be applied. Can assist in management of fibrosis, cording, scarring, lymphatic flow and pain.
Surgery	<p>Circumferential suction-assisted lipectomy (liposuction) is a procedure for a limb with lymphoedema that has become fatty and fibrotic and is unresponsive to conservative treatment.</p> <p>Microsurgical approaches include lymphovenous anastomoses.</p>	<p>Lymphatic surgery should be embedded in an integrated lymphoedema service model.</p> <p>Different surgical approaches may be of use with different presentations of lymphoedema.</p>
Wound management	Oedema has a negative impact on wound healing and the presence of wounds can exacerbate oedema. Fungal infection between toes and feet is a common entry point for microbial infection, which can lead to worsening swelling.	<p>Wound consultation with community nurses and specialist services as appropriate.</p> <p>A multidisciplinary approach is required to treat both aspects.</p> <p>Particular care is needed in management of fungal intertrigo in toes and feet.</p>
Pain management	Lymphoedema may impact upon some physical nerve changes that have occurred with treatments such as radiotherapy. Patients may therefore experience pain.	<p>Pain may affect patient adherence.</p> <p>Referral to a chronic pain management team may be appropriate.</p>

Appendix 3: LHD self-assessment tool

Measure	Example	Yes	Working towards	Action required
PRINCIPLE 1				
Are there protocols and policies in place to identify patients at high risk of lymphoedema?				
Is information relating to lymphoedema provided to patients considered at risk as part of the treatment consent?				
Is initial and ongoing education provided to people at risk of lymphoedema?				
Are there protocols and policies in place to monitor for the early detection of lymphoedema in high-risk groups?				
Have health professionals completed the HETI online training?				
PRINCIPLE 2				
Are there protocols and policies in place to ensure that people with lymphoedema are identified within 3 months of lymphoedema indicators?				
Are appropriately trained health professionals available to clinically diagnose lymphoedema?				
Are appropriately trained health professionals available to conduct comprehensive clinical assessments with people with lymphoedema?				
PRINCIPLE 3				
Are patient-centred lymphoedema education materials available?				
Are appropriately trained health professionals available to provide patient-centred education to people with lymphoedema?				

Measure	Example	Yes	Working towards	Action required
PRINCIPLES 4 AND 7				
Do patients with lymphoedema have a treatment plan appropriate to their needs?				
Are appropriately trained health professionals available to deliver evidence-based treatment to people with lymphoedema?				
Are appropriately trained health professionals available to perform ABPI when required?				
Is budget available for staffing, equipment and consumables?				
PRINCIPLE 5				
Are appropriately trained health professionals available to prescribe compression garments for all people with lymphoedema?				
Do patients receive education about garment care, replacement and funding?				
PRINCIPLE 6				
Are all patients who present with cellulitis assessed for subclinical or overt lymphoedema?				
Do patients receive education about cellulitis and its treatment?				
Are there protocols and policies in place to ensure that people with lymphoedema-related cellulitis are diagnosed, managed and referred for lymphoedema therapy?				