

Lymphedema: Issues and Interventions

By David Keast, MSc MD FCFP, Janet L. Kuhnke, RN BA BScN MS NSWOC DrPsych and Heather Hettrick, PT PhD CWS CLT-LANA CLWT

Lymphedema, also known as lymphatic edema (LE), may occur when there is a failure and subsequent overload of the lymphatic system. The condition leads to localized retention of fluid, resulting in swelling of the extremities.

The underlying epidemiology of LE can be difficult to determine. It may occur as an isolated, single condition or alongside multiple other local or systemic, sometimes life-threatening, diseases.¹ It may be caused by congenital abnormalities, trauma to the lymphatic system, lymphatic bacterial infections and/or venous congestion, resulting in protein-rich fluid in the tissues.² Determining the cause may be complicated by the challenges of quantifying (testing diagnostically) the edema severity and the changes identified to the affected tissues and surrounding skin.³

Therefore, careful and focused health assessment and history taking are essential, particularly in determining if there have been previous risk events that may contribute to development of LE, or, for example in the case of lower-extremity edema, the cause is heart failure or venous insufficiency.

Who is affected by LE?

Lymphedema affects persons at any age and occurs more often in women.⁵ In Canada, a recent analysis estimates the number of people living with LE and chronic edema to be more than a million, including persons with venous disease, obesity/morbid obesity, cancer(s), disabilities, non-cancer-related surgeries and primary or congenital LE.⁶ Clinicians frequently identify LE as a

Note: This document does not address the complexity and speciality education required to assess, treat or manage clients with compression bandaging systems, manual lymphatic drainage, simple lymphatic drainage, modified/multilayer bandaging systems, intermittent pneumatic compression, or any maintenance stocking, device or therapy.



result of cancer, yet many common risk factors for chronic edema and LE are non-cancer related and not readily identified.⁶ Identified LE causes include underlying co-morbidities such as heart failure, renal (kidney) failure, liver disease, venous reflux disease, cancers (both the cancer and the treatment/surgery), lymphatic congestion or failure, side-effects from medications, protein cal-

orie malnutrition, and local (micro) and systemic (macro) inflammatory conditions.⁴

What is the impact of LE?

Lymphedema is rarely fatal, but it can be debilitating if not diagnosed, treated and managed early. It affects a person's quality of life

Useful Definitions⁴

Lymphedema is an abnormal swelling of a limb and/or the related quadrant of the trunk due to the accumulation of protein-rich fluid in the tissue spaces of the skin.

Chronic LE is chronic edema lasting more than three months that is minimally responsive to overnight leg elevation or diuretics and is accompanied by skin changes such as thickened skin, hyperkeratosis and papillomatosis.

Primary LE is related to congenital absence or malformation of lymphatics and may appear at birth or later in life:

- If it develops before one year of age it is called Milroy's disease.
- If onset is during puberty it is often referred to as Meige's disease, or lymphedema praecox.
- If onset is after age 35 it is usually called lymphedema tarda.

Secondary LE results from damage to lymphatics.

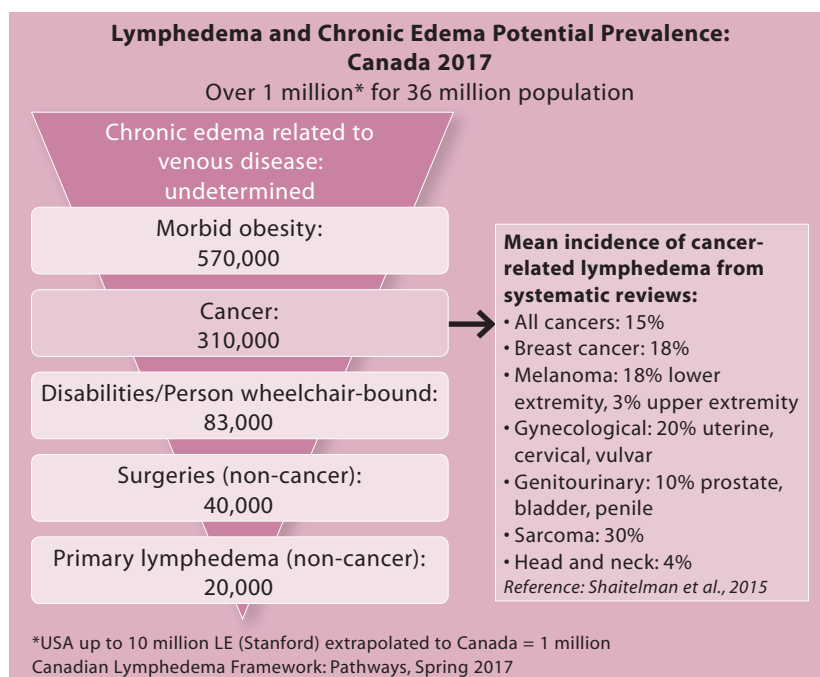


Figure 1: Lymphedema and Chronic Edema Potential Prevalence, Canada 2017⁷

and the ability to manage day-to-day activities.⁷ Persons living with LE experience psychosocial stress and physical changes that may be related to body image distortion, pain, depressive symptoms leading to diagnosed depression, skin infections and related cellulitis, reduced range of motion and subsequent reduced mobility (upper and lower limbs), loss of income and possible employment changes.⁸

Lymphedema-related swelling usually presents in the legs or arms due to an obstruction or inadequate function of a lymph channel.⁹ Congestion of the lymphatic fluid accumulates in the interstitial compartment, leading to local and extensive limb swelling that may present unilaterally or bilaterally. Though LE and chronic edema are frequently assessed in the extremities, they can occur throughout the body, and the trunk and genitals are often involved.

Types of Lymphedema: Primary and Secondary Lymphedema

Primary (idiopathic) LE occurs when a person is born with a congenital abnormality or has an

inherited abnormality of the lymphatic system.⁵ The prevalence of primary LE is 1.15 per 100,000 people.⁷ Primary LE is more common in women (lower limbs), and signs may be evident at birth or develop as an individual grows or when experiencing hormone-level changes.⁵ Keast and Towers state that based on epidemiological data, primary LE cases are estimated to affect 20,000 persons⁶ (see Figure 1).

Secondary (acquired) LE is more common and the causes are wide-ranging. Secondary LE develops when the lymphatic system is damaged or traumatized.⁵ In developed countries, leading causes of LE include cancers and radiation. The BC Cancer Agency states that tumours that obstruct the lymphatic channels or nodes occur with breast cancer, and gynecological, colorectal and genitourinary surgery, lymphoma, melanoma, sarcoma, and head and neck cancer.⁸ Radiation therapy used to treat lymph nodes, or lymph node biopsies and/or dissections can further contribute to LE development. In Canada, of growing concern is an increase in LE cases related to substantially increased rates of obesity and morbid obesity. Consequently, understanding LE is an important issue for clinicians.

In developing countries, a common cause of secondary LE is lymphatic filariasis (LF) (see Figure 2).¹⁰ LF is a severe type of edema resulting from infection from parasites (three types of filarial roundworms) that impair the lymphatic system.

LF leads to debilitating pain, deformity of body parts, emotional strain, social stigma and employment changes.¹¹ It is estimated that 1.3 billion people globally are at risk of LF infection, with more than 120 million already infected,⁴ mostly in tropical and sub-tropical regions, particularly in poor countries, where sanitation and housing are of poor quality.⁴

Stages of Lymphedema

The International Society of Lymphology presents a four-stage clinical system with associated features specifically related to the physical condition of the extremities.¹ Table 1 outlines the stages.

How is lymphedema classified?

Lymph-related edema is classified as acute or chronic (see Table 2). The true epidemiology of risk factors for the development and progression of LE remains uncertain, and more research is needed. Further complicating the identification of risk factors is that there may be a considerable delay between the causative event and the onset of LE.⁴

Consistent physical assessment includes vital signs, patient's general appearance (inspection, palpation), measurement of upper and lower limb(s) starting with the unaffected side to establish a baseline.

It Takes a Committed Team

Standards of practice have been developed under the umbrella of the International Lymphoedema Framework. This collaboration of stakeholder groups includes academics, health professionals, patients/families, industry and community organizations to promote research, best practice guidelines, and to set clinical lymphedema stan-



Figure 2: Lymphatic filariasis

dards worldwide. Current standards of practice for lymphedema services, as taken from the International Lymphoedema Framework's 2006 document titled "International Consensus: Best Practice for the Management of Lymphoedema," are as follows:¹³

Table 1: Stages of Lymphedema¹

Stage	Features
0 – Subclinical or latent condition	<ul style="list-style-type: none">• Swelling is not yet evident; there are subtle changes in fluid/tissue composition and changes in subjective symptoms.• Symptoms may exist months or years before overt edema occurs.• Heaviness and discomfort and aching are experienced.
1 – Spontaneously reversible	<ul style="list-style-type: none">• There is early accumulation of fluid relatively high in protein content (compared with venous-related edema), which subsides with limb elevation. Pitting may occur. An increase in various types of proliferating cells may also be seen.
2 – Spontaneously irreversible	<ul style="list-style-type: none">• Early stage: Limb elevation alone rarely reduces the tissue swelling, and pitting is manifest.• Later stage: Limb may not pit as excess subcutaneous fat and fibrosis develop.
3 – Lymphostatic elephantiasis	<ul style="list-style-type: none">• Swelling is present. Pitting can be absent. Trophic skin changes such as acanthosis, alterations in skin character and thickness, further deposition of fat and fibrosis, and warty overgrowths may be present.

Note: A limb may exhibit more than one stage, which may reflect alterations in different lymphatic territories.

Common Risk Factors*

As part of careful assessment and history taking, clinicians should consider the following risk factors:

- Trauma such as a sprain
- Trauma in at-risk regions due to punctures, blood pressure measurement, injections, wound/drainage complications
- Surgery that interferes with lymph nodes or vessels (lymph node dissection, breast surgery), varicose vein surgery, orthopedic surgery
- Chemotherapy (taxanes)
- Scar formation in the form of fibrosis/radio-dermatitis from post-op
- Cancer, various forms (melanoma, gynecological cancer, head and neck cancer, sarcoma)
- Intra-pelvic or intra-abdominal tumours that involve/compress lymphatic vessels
- Radiotherapy in the regions of the lymph nodes, mammary glands or pelvis (postoperative)
- Recurrent infections, infection of soft tissues
- Chronic skin disorders and inflammation
- Cording (axillary web formation)
- Seroma formation
- Obesity, poor nutrition
- Congenital predisposition
- Hypertension
- Insertion of a pacemaker
- Arteriovenous shunt for dialysis
- Living in or visiting a geographic area endemic for lymphatic filariasis
- Thrombophlebitis and chronic venous insufficiency
- Varicose vein stripping and vein harvesting
- Unresolved asymmetrical edema
- Concurrent medical illnesses such as phlebitis, hyperthyroidism, kidney or cardiac disease
- Bed/chair-dependency, immobilization and prolonged limb dependency (pelvic and genital-scrotal edema)

**Not all inclusive*

Various medications can cause edema, including calcium channel blockers (amlodipine), non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, corticosteroids such as prednisolone, and hormonal therapies such as tamoxifen for hormone-receptor-positive breast cancers.¹³

- **Identify people at risk for or with lymphedema** via systemic organization for the identification of those at risk, regardless of cause. Implement and monitor to ensure patients receive high-quality education and lifelong care.
- **Empower people at risk for or with lymphedema** through the creation of individual plans of care with emphasis on self-management developed in partnership with patients, and involving relatives and caregivers where appropriate.
- **Provide treatment services** that deliver high-quality clinical care that integrates community, hospital and hospice-based services. Provide universal access to trained health-care professionals, including specialists, that incorporates ongoing assessment, planning, education, advice, treatment and monitoring.
- **Provide high-quality clinical care for people with cellulitis/erysipelas** involving agreed-upon protocols for the rapid and effective treatment of skin infections such as cellulitis/erysipelas, as well as the prevention of recurrence. Care should be implemented and monitored by trained and certified health-care specialists.
- **Provide compression garments for people with (or at risk for) lymphedema** and provide protocols for assessment and provision of these garments.
- **Provide multi-agency health and social care** to enable comprehensive assessment for any client at risk for or with lymphedema who requires multiagency support, to ensure access and care appropriate to their needs are met by health and social services.

Why is assessing and diagnosis LE so challenging?

Careful history taking and a comprehensive assessment support identification of risk factors to distinguish LE from other conditions (see sidebar).

Early assessment and diagnosis enhance the opportunity of successful treatment and management. Investigations may include but are not limited to ultrasound to assess tissue characteristics,

Table 2: Clinical Parameters of Lymphedema

Type	Clinical Characteristics
Acute	<ul style="list-style-type: none">• Short-lived and self-limiting – less than 3 months• Imbalance of filtration and reabsorption• Local inflammation
Chronic	<ul style="list-style-type: none">• Longer-term – greater than 3 months• Minimal responsiveness to elevation of the limb(s) and/or use of diuretics and a positive Kaposi-Stemmer's sign:• The normal thickness of the skin fold at the 2nd toe is 2 to 4 mm.• A positive Kaposi-Stemmer's sign – inability to raise skin fold – means fibrosis is already present (at least Stage 2).• A negative Kaposi-Stemmer's sign does not exclude the diagnosis of LE but means the limb/patient should be monitored, as it may be too early in the LE development to show signs of fibrosis.

ankle-brachial pressure index (APBI), toe-brachial pressure index (TBPI), colour duplex Doppler ultrasound to rule out deep vein thrombosis and evaluate venous abnormalities, a screening lab panel and a filarial antigen test (if the person is at high risk).⁴ Assessment includes overall physical health, pain with and without activity, mobility, employment and work capacity, and psychosocial and spiritual well-being.

Differential Diagnosis of Lymphedema

Regardless of the underlying cause, lymphedema is a manageable condition with established interventions. In order to adequately manage the condition, early and proper diagnosis is essential.

For clinicians, one of the challenges is learning to differentiate between lymphedema and other types of edema (e.g., from health failure or venous insufficiency). Of particular importance is the current paradigm shift in thinking that all edema is the result of lymphatic drainage failure.^{14,15} This represents the prevailing thought that all edema is on a lymphedema continuum; when the body's system is overwhelmed, it results in a transient form of LE, whereas true damage or impairment to the lymphatic system leads to the disease of LE.¹⁴ For example, a sprained ankle will lead to swelling—which involves lymphatic dysfunction—which will resolve. This is sometimes called lymph stasis, because it resolves within a few weeks. If the problem does not resolve, the damage to the lymphatics becomes permanent, and at

that point would be considered lymphedema.

One of the most common forms of lower extremity LE is phlebolymphe¹⁶demia. Chronic venous hypertension leads to a high filtration pressure that results in increased fluid levels in the interstitial tissues. This excess water load begins to exceed the lymphatic transport capacity. Over time, this can lead to lymphatic hypertension that damages the lymphatic structures. When the lymphatic system becomes damaged/impaired, the high protein fluid in the interstitial tissues creates an inflammatory reaction, resulting in the fibrotic changes commonly seen in patients with chronic lymphedema. This disruption, combined with the venous insufficiency, contributes to venous ulceration. Excessive demand on the lymphatics results in a loss of fluid homeostasis. Clinically, this is seen as edema. However, the underlying pathophysiology is damage and

**Figure 3:** The effects of lymphedema

dysfunction in both the venous and lymphatic systems leading to phlebolymphe­dema—mixed venous and lymphatic disease.¹⁶

Further adding to the diagnostic challenge is lipedema, which is often confused with LE. Lipedema is a fat disorder associated with bilateral adipose deposition (typically from the ankles to the hips), and when present, it hinders and constricts lymphatic flow. However, the presence of lipedema can result in the development of LE¹⁸ and is referred to as lipolymphe­dema. Additionally, patients can present with lipedema along with phlebolymphe­dema, a condition termed *phlebolipolymphe­dema*.

As a general guideline, lymphedema or any chronic edema lasting more than three months, and minimally responsive to limb elevation and/or diuretics and with one or more secondary skin changes such as a positive Kaposi-Stemmer's sign⁶ is clinically relevant to support the diagnosis of lymphedema.

Complications Related to Lymphedema

Complications related to LE vary by individual and may involve physical signs such as swelling, heaviness in the extremity, numbness, pain and infection.¹⁸ Persons with lower-limb extremity LE report a higher symptom burden and increased infection complications (episodes of infection, hospitalizations) when compared with those with upper-limb extremity LE.^{4,18} Quality of life domains affected by LE include physical health, psychological well-being, level of independence, social relationships, environment, spirituality/religion and personal beliefs. The following section describes these aspects in relation to living with LE.²⁷

Treatment and Management Goals for Patients with LE

The following are the primary goals for treatment and management for LE patients:

- Patient education related to pain and psychosocial and spiritual issues
- Promotion of a healthy lifestyle
- Prevention of skin and tissue infections

- Creation of mobility and activity plans
- Implementation of a compression bandaging strategy and garment management
- Pharmacological management

An integrated team, which includes a variety of health-care professionals and other service providers along with the patient/family, should establish treatment and management goals for underlying diseases and conditions. For LE, overall management includes meticulous skin care and hygiene, education and patient/family engagement and participation, manual lymphatic drainage (MLD), compression bandaging, simple lymphatic drainage (SLD) involving limb elevation, and regular exercise to activate the muscle pumps (upper and lower extremities). Intermittent pneumatic compression (IPC) can help to maintain reduced limb volume; however, the long-term use of compression garments is essential to help control LE after the initial treatment phase. Although there currently is no cure, lymphedema can be successfully managed as described above, but it does require a lifelong commitment. Throughout this time, communication among team members and across settings (home and community care, long-term care, rehabilitation unit, and acute or emergency care) is crucial. It is essential that clinicians collaborate with the patient and work as a team to identify key persons who will support and aid the patient in all decision-making and activities throughout the lifelong LE management process.

What do you see, and how do you treat LE?

Skin Complications/Infections

The Impact

Disorders of the lymph system, whether systemic (macro-lymphedema) or localized (micro-lymphedema), produce cutaneous regions susceptible to infection, inflammation and carcinogenesis.^{20–22} Some of the most common skin complications include:

- Dryness (cracked, flakey, rough); fissures
- Cellulitis/erysipelas (infection of the skin and

Figures 4 to 8: Common Skin Complications Caused by Lymph System Disorders



Figure 4: Dry skin



Figure 5: Taut, shiny skin



Figure 6: Papillomatosis



Figure 7: Skin folds



Figure 8: Lymphorrhoea

Images used with permission (Keast, 2017).

- subcutaneous tissues most commonly caused by streptococci and *Staphylococcus aureus*)
- Hyperkeratosis (over-proliferation of the keratin layer, producing scaly grey or brown patches)
- Folliculitis (inflammation of hair follicles)
- Fungal infections
- Lymphangiectasis, also known as lymphangioma (soft fluid-filled projections caused by dilations of lymphatic vessels)
- Papillomatosis (raised firm projections on the skin due to dilatation of lymphatic vessels and fibrosis. This may be accompanied by hyperkeratosis.)
- Lymphorrhoea (occurs when lymph leaks from the skin surface)
- Ulcerations (occurs with underlying arterial and venous disease)
- Venous eczema (also known as varicose eczema,

or stasis dermatitis)

- Contact dermatitis (an allergic or irritant reaction)
- Lymphangiosarcoma (a rare form of lymphatic cancer)^{4, 10, 13}

The Interventions

Prevention of skin damage such as cuts and irritations for patients at risk for or with LE involves consistent skin hygiene and care to keep the skin intact, clean, dry and moisturized. Cuticles should not be cut, and artificial nails should not be applied on patients with upper extremity LE. If skin damage occurs, the area should be washed and patted (not rubbed) dry, and hydrating, low-pH lotions and/or emollients applied. If needed, and in consultation with a physician/nurse practitioner, topical antibiotics should be applied and progress monitored. Signs of possible infection

include rash, itching, increased skin temperature or fever, and flu-like symptoms. Any symptom should be monitored and reported to a health-care professional.⁴ Pain is reported in 50% of persons with LE and associated skin complications, so proper management is essential, as it affects a person's well-being and ability to cope and participate in care.¹³

Skin care for the limb at risk for or with LE includes the following:

- Monitor skin, especially in less visible areas. Skin should be monitored daily for dryness, cuts, scrapes or bruising on the limb or affected area. It is important to look between the toes and fingers and under skin folds if present.
- Avoid any type of constriction on the affected limb, such as tight clothing, shoes and jewellery, as well as blood pressure cuffs and venipunctures.
- Assess and treat infection if present with the proper dressings and compression bandages.
- Maximize nutritional status with a referral to a registered dietitian.
- Manage moisture, with a referral to a nurse specialized in wound, ostomy and continence.
- Assess and address for continence if appropriate, with a referral to a nurse specialized in wound, ostomy and continence, and/or a nurse continence adviser.
- Assess pain using a validated tool, and manage the pain based on the assessment.

Level of Independence – Mobility and Range of Motion

The Impact

Limb weight may preclude a patient living with LE from engaging in and performing activities of daily living and instrumental activities of daily living. Immobility primarily refers to lower extremity edema and failure of the calf-muscle pump, and includes those with fixed ankles and those who are chair-bound.⁶ Maintaining adequate levels of energy, managing fatigue, and achieving sleep and rest are important for supporting patient activity plans. Clinicians should emphasize to the patient that being active improves lymphatic and venous flow to reduce limb size/volume. There should be

ongoing and consistent measurement of the limb's affected area and comparison to baseline.

The Interventions

Maintenance of a healthy weight in persons at risk for LE or who are obese has been shown to be of benefit.^{1,23–25} Nutritional support to optimize weight in combination with activity and exercise benefits the patient's overall health. It is important to monitor the affected area during and after activity for changes in size, shape, texture, soreness and similar symptoms.⁴ Rest periods between work and activity allow for limb recovery.⁴

Functional care planning includes the following:

- Optimize mobility and activity through light exercises that encourage lymph drainage. All exercise should be performed while wearing compression bandages or garments. Clinicians should refer their patients to a certified lymphedema therapist, who will be expert at assessing and treating the condition. These therapists may be nurses, physiotherapists, occupational therapists and massage therapists who have undergone specialized training to meet national training standards.²⁶
- Ensure equipment and mobility aid(s) are frequently assessed and monitored, as a patient's needs may change.
- Assess and modify situations where the affected area is experiencing pressure from equipment, garments, medical-devices and clothing (e.g., sitting, standing or crossing legs).
- Refer the patient for professionally fitted compression hosiery. If personal finances preclude obtaining appropriate garments, the clinician should refer the patient to a social worker or other appropriate support professional.
- Ensure the patient protects limb tissues while engaged



in activity. Clinicians should refer the patient to a certified garment specialist for long-term management. Limbs that are at risk should have compression for strenuous activities except where there are contraindications such as open wounds or poor circulation.⁴

- Encourage the patient to obtain professionally fitted footwear.
- Assess the ability of the patient to safely participate in work or school, social and leisure activities through self-pacing, protection of the limb and skin, and learning the most efficient and safe way to participate. Referrals can be made to an occupational or physical therapist for support.
- Prevent falls through education about fatigue and about the correct use of equipment and devices.
- Discuss proper sleep hygiene and positioning with the patient.

Management of LE

The Impact

Day-to-day management of LE includes the use of compression. The proper type of compression will be prescribed and may include compression hosiery, stockings, hook-and-loop fastened devices or wraps, sleeves, bandages, night garments, bandaging systems (modified/multilayer inelastic lymphedema bandaging [MLLB]), and intermittent pneumatic compression used to encourage fluid management back to the trunk of the body. These

treatments vary and may be used in combination depending on the situation.

The Interventions

The standard of care for the management of LE is complete decongestive therapy (CDT).¹ Interventions focus primarily on decreasing the edema to return the limb to normal, or as close to normal as possible. Early assessment and treatment are

essential.⁴ Certified massage therapists,²⁷ certified compression garment therapists and nurses play an important role. Therapy includes providing skin care and hygiene, manual lymph drainage (MLD), compression therapies such as intermittent pneumatic compression (IPC), exercise, and extensive patient education for lifelong self-management.²⁸

Once the limb has been decongested and has returned to as near normal as possible, ongoing therapy and protection of the limb are essential. All aspects of complete decongestive therapy should be continued by the patient or with assistance from a caregiver or family member, for life. If the patient has skin breakdown or open wounds, single-use bandage systems (2-, 3-, or 4-layer) can be used until the wound or skin issue has resolved, in combination with appropriate wound management. Patients should wear appropriate compression for their skin condition, lymphedema and lifestyle at all times other than during personal hygiene activities. For patients requiring long-term use of garments and devices, education should be provided to the patient/family and caregivers. Clinicians should provide education to patients, family and caregivers regarding the care, washing and drying of each garment, and should support patients if finances preclude them from obtaining appropriate garments.

Psychological Health

The Impact

Psychological health is affected when learning about and learning to live with LE. Living with LE is complex and is associated with poor self-esteem, altered body image, depression and anxiety.⁴ In addition, loneliness, isolation and loss of sense of self can interfere with one's ability to cope. Lowered well-being may affect the patient's ability to engage and participate in their health-care decisions, family relationships and community. Patients may present with distress, poor coping skills and limited engagement with caregivers and treatment planning.¹³

The Interventions

It is important use validated tools to screen for depressive symptoms, depression, anxiety, feelings



of worthlessness and reduced hope. If feelings of worthlessness, depression or anxiety persist for longer than three months, the patient should be referred to mental health services.¹³ Psychologists, social workers and counsellors may offer therapy, counselling and culturally relevant supports. Sleep and rest patterns should be reviewed. Some patients may benefit from complementary and alternative therapies (relaxation therapy, mindfulness, mind-body therapy) as is reported in populations living with chronic illnesses.²⁹ Furthermore, the role of traditional, cultural or folk healers should be considered.³⁰ Delivery of culturally sensitive education for the patient and family members is of benefit. It is important that the focus be on LE prevention and management strategies, including the benefits of activity, exercise and relaxation to help the patient adapt.^{31–32} For employed patients and those in active volunteer roles, clinicians should consider their work-ability, and support work adaptations as needed. Caregiver burnout can be prevented by engaging and supporting the family unit.

Social Activities

The Impact

Adapting to life with LE may be challenging. Changes in body image, the perception of self, sexual activity and the ability to participate in social activities may change or be impeded. It is important when living with a chronic disease to maintain social contacts and engagement with friends, family and community.

The Interventions

Clinicians should consider referring the patient to and engaging the patient in a chronic-disease self-management program³⁵ and, if possible, encourage family members or close friends to attend classes. Self-management of LE is complex and includes a modified version of complete decongestive therapy.³⁴ In addition, self-care includes lifestyle modifications, nutrition and weight management, organization of medical appointments and day-to-day management of other aspects of living. As patients' underlying health issues change, so does their ability to

manage self-care when living with LE, which needs to be taken into consideration when planning long-term care.

Patients should be encouraged to participate in treatment and management planning as much as possible. Clinicians should be conscious of caregiver fatigue and burnout. For patients with cognitive impairment or fatigue, family members or friends should be engaged as a care partner in communication and decision-making as part of the integrated care team.³⁵ Throughout the process it is important that the clinician provide privacy and build trust, so the patient feels free to discuss issues relating to sexual activity and intimacy.

Spirituality

The Impact


Patients living with LE often receive hope, solace and encouragement from friends and family members through their spiritual values, beliefs and traditions.³⁶ Health-care professionals are in a unique position to encourage clients regarding their spiritual health, as it can promote psychological well-being and emphasize holistic care. Spirituality is defined as the patient's "belief in and experience of a supreme being or an ultimate human condition, along with an internal set of values and active investment in those values, a sense of connection, a sense of meaning, and a sense of inner wholeness."³⁷ Hengen further describes spirituality as a balance between a client's social, emotional, and spiritual wellness;³⁸ this is not just an individual process, as individuals live in social circles and in community.

The Interventions

Spiritual wellness, while adapting to life with LE, may be challenging, as one's ability to participate in spiritual readings and meditations, religious and faith-based activities or rituals may be altered. Conducting a spiritual assessment encourages the patient to remain connected with their practices, faith or religious community. Patients often identify more strongly with health-care professionals who assess them as whole individuals with spiritual needs. Any spiritual well-being assessment should be conducted using a

validated tool, for example the HOPE Approach to Spiritual Assessment; Spiritual Assessment Tool.³⁹ Clinicians should support their patients by encouraging them to be in contact with members from their spiritual community and spiritual leaders. These efforts support the patient's psychological health and well-being.

Conclusion

Living with LE is complex. This paper has focused on key complications, assessment, and conducting a careful history taking and a focused health assessment, as well as identification of interventions and considerations for patients living with or at risk for LE. Patients with LE experience physical, psychosocial and spiritual issues and require care from an integrated care team. Communication and education are essential for proper assessment, treatment and management. 

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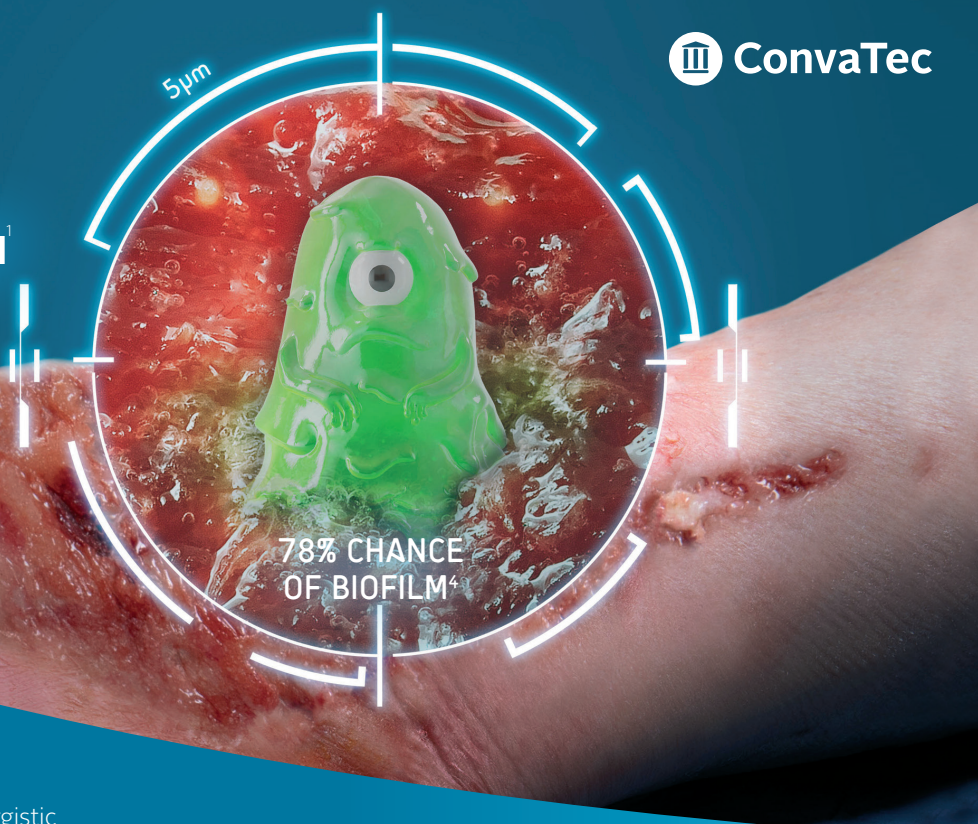
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