




INTERNATIONAL  
LYMPHOEDEMA  
FRAMEWORK

**Position  
Document**



# THE MANAGEMENT OF LYMPHOEDEMA IN ADVANCED CANCER AND OEDEMA AT THE END OF LIFE

International Lymphoedema  
Framework and Canadian  
Lymphedema Framework

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# 1. Introduction

This Position Document aims to provide the clinician with approaches to the management of oedema and its associated complications at the end of life. Specialist therapeutic interventions, embedded in the palliative care ethos of multidisciplinary care to reduce symptoms and associated psychological distress, improve quality of life and reduce attendant risks, are defined.

The World Health Organization (WHO)<sup>i</sup> states that '*Palliative care aims to provide relief from all symptoms, and aims to offer support to the individual to live as actively and independently as possible until death*'. Oedema at the end of life occurs as a direct result of disease, or as a result of multiple factors relating to a terminal illness. Oedema in advanced cancer signifies deterioration and as such, can be both distressing for the patient and their family<sup>ii</sup>, and a management challenge for health care professionals.

The true prevalence of oedema at the end of life is thought to be around 5–10 % of all new referrals<sup>iii</sup>, although this is likely to be an underestimate. Internationally, we need to develop minimum datasets to fully gauge the impact of oedema at the end of life and work with end of life care initiatives to ensure equitable access to treatment for all.

The goals of treatment within the palliative setting are different than traditional lymphoedema therapy. Therapy is patient centred, adapted to meet their needs and regularly reviewed to determine their benefit. Through open and honest communication and team working, the lymphoedema therapist can forge meaningful relationships with the patient and their families. Perseverance and adaptability are a necessity, and for the patient, small improvements in swelling or the cessation of lymphorrhoea can be hugely significant. Lymphoedema interventions can make a very real difference to the quality of life for patients with oedema at the end of life.

The main principles of the care approach are outlined in Box 1. This document, led by the Canadian Lymphedema Framework in partnership with the ILF as part of a strategy to address all aspects of lymphoedema management, represents an international approach to standardising care for these patients.

## References

- i. World Health Organisation  
<http://www.who.int/cancer/palliative/en/>
- ii. Frid, M., Strang, P., Friedrichson, M., *et al* (2006) Lower Limb Lymphoedema (LLL): Experiences and Perceptions of cancer patients in the late palliative stage. *Journal of Palliative Care*. Toronto, Spring Vol 22 (1) 5-9
- iii. North London Cancer Network/ Derby & Burton Cancer Network (2006/2010) Lymphoedema Service/ Commissioning Framework reviews (unpublished)

### Box 1: Principles of care for the patient with end of life oedema

- The patient is at the centre of oedema assessment and treatment plan - what appears to be problematic to the health care professional may not be the patients overwhelming concern
- Assessment of oedema is part of the overall specialist palliative care assessment. Referrals are made for physical, psychological and social support as required
- Specialist palliative care health care professionals can assess and treat non complex oedema at the end of life after appropriate training in adapted multi layered bandaging
- Therapy aims to relieve symptoms, improve quality of life and reduce risk associated with the oedema
- Family and caregivers should be involved in simple adapted treatments where necessary and desirable
- Reassess regularly to identify contra-indications, assess the benefit of treatment, and changes in clinical condition

## 2. Pathophysiology and presentation of oedema in advanced cancer and the end of life

Oedema is a common feature of many chronic conditions including:

- Advanced cancer
- Chronic heart failure
- Advanced neurological and liver disease
- End stage renal disease
- End stage chronic respiratory disease
- HIV / AIDS

Due to the general frailty and weakness which many patients with advanced disease experience, the routine 'intensive' management of oedema using decongestive lymphatic therapy may not be appropriate. A 'palliative' approach that will relieve symptoms and improve quality of life is required, provided that the likely benefit of treatment is weighed against any potential burden. Oedema in advanced disease is often multi-factorial in origin, so an understanding of the contributing components and whether they can be improved will influence overall management. In patients with advanced cancer, oedema is recognised as a poor prognostic indicator<sup>1</sup>.

### Pathophysiology

The accumulation of oedema is caused when net capillary filtration in the relevant anatomical site exceeds lymphatic drainage. The filtration of fluid from blood capillaries into the interstitial space is determined by:

- The hydrostatic pressure gradient between the fluid in the capillary and that in the interstitial space
- The opposing colloid osmotic pressure gradient due to the plasma proteins within the capillary (which are not filtered out into the interstitial space)
- The permeability of the capillary wall

Lymphatic drainage is determined by:

- The functional integrity of the lymphatic system; that is, the normal function of the intrinsic muscle pump in the walls of the larger lymphatics and the lack of damage to the lymph vessels and nodes
- The extrinsic muscle pumping from skeletal muscles during movement

In patients with advanced disease and at the end of life, a number of factors can affect both capillary filtration and lymphatic drainage (table 1).

**Table 1: Factors affecting capillary filtration and lymphatic drainage**

#### Factors which can increase capillary filtration

##### ■ Venous hypertension

**Local;** extrinsic venous compression, venous thrombosis, immobility (muscle pump failure)

**General;** heart failure (with or without anaemia), drugs

##### ■ Hypoalbuminaemia anorexia/cachexia, proteinuria

#### Factors which can impair lymphatic drainage

##### ■ Previous surgery / radiotherapy

##### ■ Metastatic lymphadenopathy

##### ■ Long standing increased flow (high output failure)

##### ■ Immobility

Because of this complex aetiology, the terms 'oedema' or 'chronic oedema' are preferred to lymphoedema. While it can be argued that all oedema has a lymphatic component, in many conditions lymphatic damage is not the primary cause. The most common components of oedema in advanced diseases are:



### Advanced cancer

- Previous surgery / radiotherapy
- Metastatic lymphadenopathy
- Immobility
- Extrinsic venous compression (including vena cava obstruction)
- Venous thrombosis
- Drugs
- Hypoalbuminaemia

### Chronic heart failure

- Venous hypertension ( $\pm$  ascites)
- Immobility
- Hypoalbuminaemia (anorexia / cachexia)
- Anaemia (exacerbates heart failure / venous hypertension)

### Advanced neurological disease

- Immobility

### End stage renal disease

- Venous hypertension ('fluid overload')
- Hypoalbuminaemia (proteinuria)
- Immobility

### Advanced liver disease

- Venous hypertension
  - 'fluid retention' due to hyperaldosteronism
  - portal hypertension + ascites
- Hypoalbuminaemia
- Immobility

### End stage chronic respiratory disease

- Immobility
- Heart failure (cor pulmonale)
- Hypoalbuminaemia (anorexia / cachexia)

Drugs may contribute to the development or severity of existing oedema. Examples include:

- ▶ Calcium antagonists
- ▶ Corticosteroids

- ▶ Non-steroidal anti-inflammatories
- ▶ Sex hormones
- ▶ Anticonvulsants
- ▶ Anti-Parkinsonian
- ▶ Antidiabetics
- ▶ Bisphosphonates
- ▶ Cytotoxic chemotherapy

Conversely, drugs such as corticosteroids, diuretics and aldosterone antagonists can help manage oedema.

### Signs and symptoms

The appearance and clinical features of oedema depend upon the underlying aetiology and its duration. 'Conventional' lymphoedema usually presents in an anatomically discrete region depending upon the cause; for example, a swollen arm following treatment for breast cancer. In the early stages, it presents as 'pitting', but as the chronic inflammatory process progresses, fibrosis and adipose tissue deposition occurs and the subcutaneous tissues become firmer, but will still usually "pit" to more sustained higher pressure. The typical skin changes of lymphoedema are

- Thickened skin
- Hyperkeratosis
- Lymphangiectasia
- Papillomata

A positive Stemmer's sign will also indicate lymphoedema, although a negative Stemmer's sign does not exclude it.

Up to 67% of patients with advanced cancer experience pain due to oedema: heavy, swollen limbs can cause proximal pain; for example, hip and back pain with leg oedema. Patients with active malignancy may experience neuropathic pain as a result of nerve compression or destruction.

### Complications

The most common complications of lymphoedema are cellulitis and lymphorrhoea (leakage of lymph fluid). Oedema associated with dependency/immobility, heart failure and liver disease, is often extensive, very soft and easy to "pit". The skin may be thinned and stretched, and may break, causing lymphorrhoea. In advanced liver and heart disease, ascites may be present.

Immobility due to generalised weakness and the weight of the swollen limbs leads to a greater accumulation of oedema fluid as the leg muscle pumps are impaired.

Pathophysiology and presentation of oedema in advanced cancer and the end of life

Clinicians should be aware of the risk of deep vein thrombosis (DVT), as it may be masked by the oedema; a common indicator is a rapid increase in oedema. The most common presentation of DVT in patients with advanced cancer is asymmetric bilateral leg oedema<sup>2</sup>.

Patients with active malignancy may experience neuropathic pain as a result of nerve compression or destruction. Up to 67% of patients with advanced cancer experience pain due to oedema<sup>3</sup>: heavy, swollen limbs can cause proximal pain; for example, hip and back pain with leg oedema.

**Common presentations of oedema**

*Locally advanced breast cancer*

Oedema of the arm and chest wall is a result of locally advanced breast cancer, particularly with axillary lymphadenopathy and chest wall disease. Tumour infiltration of the dermal and subcutaneous lymphatics decreases the number of pathways available for lymph to drain, and co-existing brachial plexopathy will contribute to limb immobility and further oedema (figures 1 and 2).

*Advanced pelvic malignancy*

Oedema of the legs, genitalia and lower abdomen may be a feature of advanced pelvic malignancy. It can be part of a so-called "pelvic syndrome" with other associated symptoms such as neuropathic pain, bladder spasms, fistulae, haemorrhage and malodorous exudate<sup>4</sup> (figure 3). The oedema is often soft and pitting and may extend to the chest wall; lymphorrhoea is common.

Factors involved in the aetiology of oedema of advanced pelvic malignancy include:

- Underlying post-treatment (surgery/radiotherapy) lymphoedema
- Metastatic pelvic and para-aortic lymphadenopathy
- Extrinsic venous compression by tumour
- Inferior vena cava obstruction<sup>1</sup>
- DVT
- Hypoalbuminaemia
- Malignant ascites
- Anaemia

*Facial oedema in advanced head and neck cancer*

Radical radiotherapy and lymphadenectomy by neck dissection for head and neck cancer may lead to lymphoedema. This typically affects the lower part of the face, particularly the submental region. In recurrent disease, particularly with cervical lymphadenopathy, more extensive



Figure 1: Advanced invasive breast cancer

Figure 2:  
Fungating  
breast  
cancer



Figure 3: Advanced pelvic malignancy



soft pitting oedema, which can involve the whole face including the eyelids, may develop (figure 4). Typically, the swelling is worse first thing in the morning and improves a little as the day goes on, because the eyelid swelling settles and the fluid seems to "gravitate" down to the lower cheeks and submental region.

### Heart failure

Peripheral oedema is a typical feature of chronic heart failure; those with severe disease may develop widespread oedema, including ascites. Many patients with heart failure become relatively immobile thus exacerbating peripheral oedema (figure 5). As their condition deteriorates, the oedema may improve spontaneously as hypotension causes a reduction in capillary filtration.

### End stage neurological disease

Here, oedema is generally related to immobility; typically, the oedema develops in the lower limbs and progresses as mobility reduces. In conditions such as Parkinson's disease, swelling may be asymmetrical as the weaker side is usually more oedematous. The oedema is soft and pitting, but depending upon the duration of the illness, may develop more chronic changes.

### End stage renal disease

More than one fifth of patients with end stage renal disease experience oedema as fluid overload may become intractable even with dialysis. Hypoalbuminaemia may contribute.

### End stage respiratory disease

Here, immobility or cor pulmonale can lead to extensive soft, pitting peripheral oedema.

### End stage liver disease

Patients often develop ascites, jaundice, hepatic encephalopathy and bleeding from oesophageal or gastric varices secondary to portal hypertension. Hypoalbuminaemia is often a feature.

## Conclusion

Oedema in advanced cancer and other end stage chronic conditions usually has a complex aetiology. An understanding of the components involved enables a more complete assessment and facilitates decision-making with regard to management.

Figure 4: Head and neck swelling secondary to cancer



Figure 5:  
Swelling due to heart failure





# 3. Assessment: prioritising the goals of the palliative care model

Oedema at the end of life is common and causes varied problems for patients. This can range from patients with chronic oedema needing continued management into the last weeks of life but with altered goals, to severe progressive oedema due to an advancing cancer, causing debilitating symptoms. In any case, the benefits of management are restricted by the progressive nature of the underlying illness, concurrent symptoms and a limited prognosis. It is important to improve and control symptoms as much as possible. Assessment is the first step.

## Holistic assessment and multidisciplinary team (MDT) working

Supportive, palliative and specialist palliative care services are described in The National Institute for Health and Clinical Excellence's (NICE) *Improving Supportive and Palliative Care for Adults with Cancer*<sup>6</sup>. The key principles should be applied to assessment:

- Consider the patient as a whole person; integrate physical, social, psychological and spiritual care
- Focus on quality of life rather than quantity
- Aims of management should be decided by the patient with consideration of the family/loved ones needs
- Ensure good communication for effective assessment and management

Who is involved in a patient's care and makes the initial assessment will depend on the underlying illness and complexity of symptoms. Non-complex palliative care needs will be met by the General practitioner and community nurse. Specialist teams, such as oncology for cancer diagnoses, or cardiology for heart failure, continue to be involved whilst they have palliative therapies to offer. Specialist Palliative Care Services become involved for patients with complex problems, whether physical, social,

psychological or spiritual. This service:

- Comprises a multidisciplinary team of professionals who specialise in palliative care: the hospice/ specialist palliative care (in-patient) unit, community and hospital palliative care teams, palliative care day centres, and palliative medicine out-patient clinics
- Addresses complex and unresolved symptoms and psychosocial concerns, working alongside the primary care team
- Provides palliative care education and training

## Assessment of a patient with palliative care needs

The aim of assessment is to understand:

1. The patient's main concerns, priorities and goals. There is little point focussing on a professional concern if it is of no consequence to the patient.
2. The cause of, and mechanisms behind, the oedema. Management should be focused on the interventions most likely to produce an improvement.
3. The stage of the underlying condition and how quickly it is progressing. It is important to set achievable goals within this context.

## History of oedema

### Physical

- Is this a new complication or a previously controlled oedema that has recently progressed?
- How long has it been present, how quickly is it increasing?
- Any factors that have made it better or worse?



## Assessment: prioritising the goals of the palliative care model

- What symptoms is it causing? For example, pain, tightness/stiffness and heaviness (*figure 6*)
- What effect is it having on the patient's physical abilities and daily activities?
- Are there other symptoms such as neuropathic pain (local nerve infiltration), musculoskeletal pain, lymphorrhoea, areas of inflammation or cellulitis?

Patients may not volunteer all the symptoms, particularly if they think there is no treatment or the professional will not be interested<sup>6</sup>. Tools such as the Palliative Care Outcome Score (POS) and Memorial Symptom Assessment Scale (MSAS) have been used to assess, measure and monitor symptoms, but can be time-consuming to complete<sup>7,8</sup>.

### Social

- Physical abilities will be affected by oedema and progressive illness - how has this affected their role, for example as a parent, wage earner, carer?
- What are the consequences; are there financial concerns and have benefits been applied for? Are they still able to carry out self-care?
- What support (family and friends) do they have?

### Psychological

- Psychological responses to deteriorating health and associated losses vary both for different patients and in the individual; altered physical form and/or role in life can produce feelings of worthlessness
- Sadness is a normal reaction and can be difficult to differentiate from a depressive illness. The Hospital Anxiety and Depression Scale (HADS) is a useful screening tool in palliative care<sup>9</sup>
- Denial is a coping strategy but will prevent honest communication and goal setting, so professionals must manage this sensitively
- Enquiring about a patient's known coping strategies, past experience of illness and history of mental health problems will help understand and support their current coping

### Spiritual

- Patients will have a range of thoughts, questions, concerns and distress; they may ask existential questions such as 'why is this happening?'

**Figure 6:**  
A heavy,  
lymphoedematous  
limb causing  
neuropathic pain  
and decreased  
function



### History of illness

It is important to understand the underlying illness causing the deterioration. What is the diagnosis, stage or spread of the disease? What treatments have they had that might cause oedema? What are they still receiving that may improve symptoms?

Information should be collected from a variety of sources, such as the patient's understanding, a collateral history from their loved ones/carers and objective information from medical notes or liaison with the patient's doctor.

This will inform:

- The pathological reason for the oedema and other symptoms
- The rate of disease progression and prognosis
- The level of understanding a patient has

### Medication

There are many drugs that may cause or exacerbate oedema<sup>10</sup>. Patients' with palliative care needs are likely to be taking a number of medicines. Some of them may be implicated in the development of their oedema (*see section 2*), so it is important to note current medication and those stopped or started recently. Corticosteroids (steroids) are used to manage a variety of symptoms in palliative care including reducing some types of oedema. However steroids can cause oedema and when taken over a longer period of time (weeks to months) they can also cause non-oedematous swelling.

### Communication

The importance of good communication cannot be underestimated.

- Listen to the patient to understand their main concerns, underlying fears and anxieties. Check that your understanding is correct
- Check what information the patient wants to receive; one will feel reassured by detailed information, whereas another will be overwhelmed

## Assessment: prioritising the goals of the palliative care model

- Explain to the patient (and loved ones) the cause of oedema, management and anticipated outcome, and check their understanding
- Provide an opportunity to ask questions or voice concerns
- Assess the relatives/loved one's understanding and needs and help them support the patient

### Examination

1. Assess the oedema as this provides a baseline for assessing response to treatment and identifies risk of future complications.

2. Look for signs that will suggest or confirm the cause of the oedema or any aggravating factors.

#### When assessing the oedema consider:

- Adapting volume measurements according to the patient's abilities. Measurements are not necessary if there is no expectation of improving the volume
- The extent of the oedema - what appears to be lower limb swelling may extend to the sacrum, torso or genitalia and therefore alter management (*figure 7*)
- Any pitting - this can range from very soft, to pitting only with sustained pressure

Skin condition - thinned and translucent skin is at risk of lymphorrhoea. Even when oedema cannot be reduced, very light compression will improve the skin condition and prevent additional complications

- Differentiating between generalised inflammation due to severe oedema and infection

- Any wounds such as fungating tumours or ulcers - note the site, size, depth, tissue type and evidence of bleeding, leakage or infection (*see section 6*)
- The effect on the patient's movement/function; note any compounding factors such as generalised weakness and muscle wasting (cachexia) or paresis due to specific nerve damage

#### Possible causes/aggravating conditions of oedema:

##### Tumour

There may be obvious tumour proximal to the oedematous area; note the position, size and condition of the overlying skin. Skin lesions and fungating tumours can be aggravated by the active movement of tissue fluid, for example, increasing leakage from a fungating tumour. The presence of a visible obstruction to lymph flow does not preclude a simultaneous thrombosis.

##### Deep Vein Thrombosis (DVT)

DVT will cause a sudden increase in oedema. The limb may look engorged or plethoric (bluish).

##### Superior Vena Cava (SVC) and Inferior Vena Cava (IVC) compression/infiltration

The Vena Cava can be compressed or infiltrated by tumour and/or thrombosed causing obstruction. In SVC obstruction this produces a typical pattern of head and upper limb oedema, plethora and prominent chest wall veins. In IVC obstruction the pattern is bilateral leg oedema extending to the torso with prominent abdominal wall veins.

##### Hepatomegaly

Hepatomegaly caused by multiple metastases can compress the IVC and be associated with deteriorating liver function and lowered albumin levels. Jaundice is first visible in the sclera of the eyes.

##### Ascites

This abnormal accumulation of fluid inside the peritoneal cavity causes abdominal distension and frequently, lower limb oedema. Specific examination techniques, 'shifting dullness' and 'fluid thrill', can confirm the presence of ascitic fluid.

##### Heart failure

May be a primary or concurrent diagnosis; the physical signs of right and left heart failure should be sought, for example, raised jugular venous pressure, respiratory crackles, and sacral oedema.

##### Supplemental intravenous fluids

The physical changes occurring in the terminally ill patient

**Figure 7:**  
Unilateral swelling secondary to gynaecological cancer



## Assessment: prioritising the goals of the palliative care model

affects fluid balance - fluid is more likely to move into the tissue space and aggravate oedema.

### Investigations

The cause of oedema can be understood from a combination of history, examination and previous tests. Further investigations should only be undertaken if the results would alter the course of management. These may include:

- Blood tests for anaemia, raised white cell count, C-reactive protein albumin and d-dimers
- Venous Doppler Scan of the relevant limb(s) for DVT
- Abdominal ultrasound scan to confirm liver metastases or ascites and guide drainage
- A CT scan to identify proximal thrombosis or compression of the IVC/SVC, or to restage disease

### Patients' goals of management

The management plan is tailor-made for the individual patient by taking in to account:

1. The patient's priorities.
2. The specific causal mechanisms and aggravating factors.
3. The anticipated progression of the oedema and underlying condition.

The management goals are individualised. The shorter a prognosis, the greater the emphasis on managing today's

problem without concern for future complications; for example, the long term side effects of steroids will not be an issue. Thus, rather than reducing oedema significantly, realistic goals may include limiting increasing oedema, reducing lymphorrhoea, improving discomfort and adapting to altered physical abilities with aids.

Many patients will be open and able to make plans 'hoping for the best while 'planning for the worst'. It is also normal for patients to express a mixture of realistic and unrealistic hopes, recognising deterioration when it occurs, but not planning ahead. Others, even with appropriate support, may not be able to acknowledge or discuss their changing health. Health professionals need to adapt their approach accordingly, setting goals sensitively whilst remaining professionally realistic about the expected outcome.

### Conclusion

Thorough assessment is the key to successful management of oedema in advanced cancer and at the end of life. Enquiry into the presence of oedema and associated problems should be integrated into the general assessment of patients with palliative care needs. Assessment and management of oedema in this context should be adapted, with a palliative care approach in order to meet the patient's different needs. Understanding the patient's wishes and setting realistic goals with them, within the limits of their illness, is central to the assessment process.

# 4. Adapting CDT for the palliative patient: specifics of management when treating with CDT

Oedema in the palliative patient is often of mixed aetiology and a challenge to manage. Many patients suffer from lower body lymphoedema/mixed oedemas, which require techniques to manage. Individualised and flexible treatment plans are vital to ensure the comfort and effective management of the patient and their family.

## General principles governing the elements of CDT

Complete/complex decongestive therapy (CDT) comprises two treatment phases and five modalities that work in concert to comprehensively address lymphoedema. The following overview functions as a comparative between standard and palliative approaches to care delivery (figure 8).

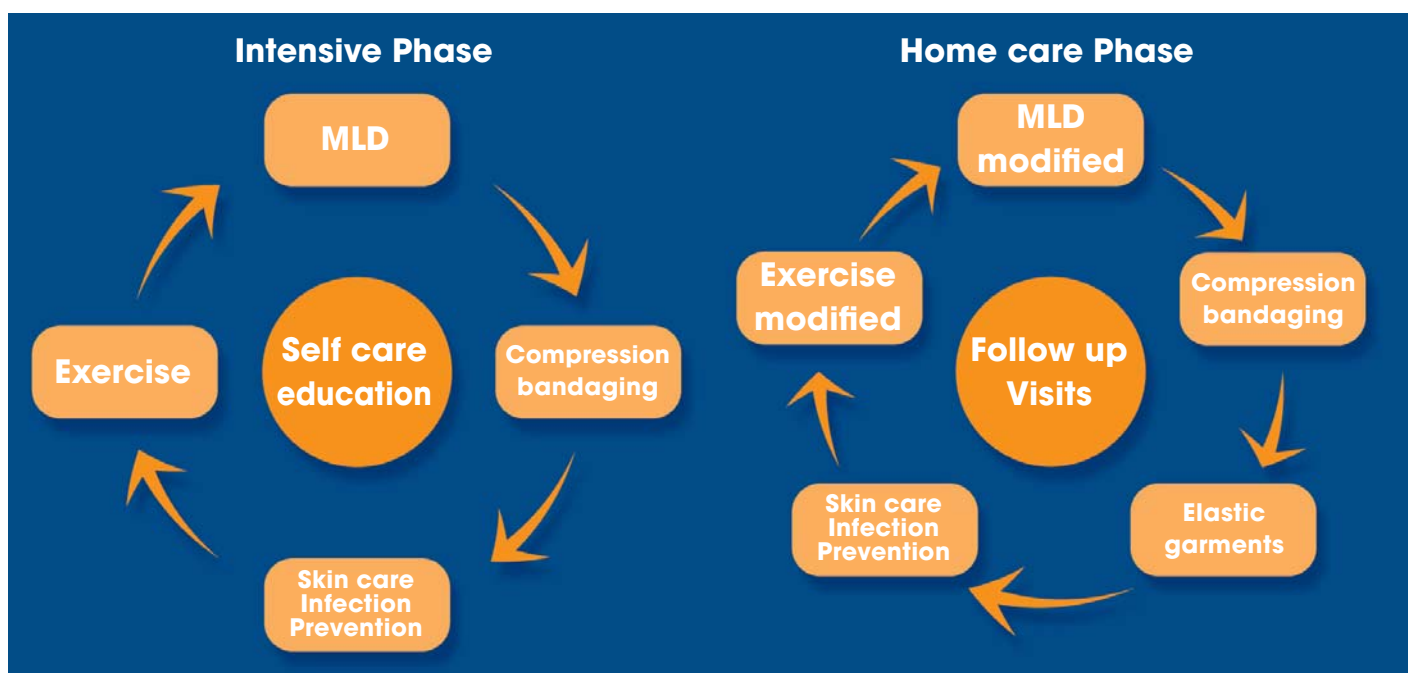
### Manual Lymph Drainage (MLD)

MLD provides direct stimulation to lymphatic tissues resulting in a reflexive increase in the uptake and transport of lymph. Further improvement in lymph transport results from decongestion of the deep lymphatic structures such as the thoracic duct, right lymphatic duct, lymph trunks (table 2).

### Compression Bandaging

Compression bandaging reduces oedema as a result of increased tissue pressure, and when combined with MLD as a pre-treatment, outflow of lymph accelerates via lymphatic collectors while water is absorbed locally through vein walls (table 3).

Figure 8: Standard CDT (Foeldi Method)





**Table 2: Principles and effects of MLD**

Principles	Rationale	General Effects
<b>Decongest central areas first</b>	Progress from the deep system (subfascial, visceral) to epifascial. Treat node basins first, then the territories of respective nodes	<ul style="list-style-type: none"> <li>■ Increased lymph production</li> <li>■ Increased lymphangioactivity</li> <li>■ Relax the patient, sooth discomfort</li> <li>■ Analgesic relief (gate effect)</li> <li>■ Diuretic effect</li> </ul>
<b>Increase and sustain lymphangioactivity</b>	Lymph time volume is increased, limb reservoirs are emptied, kidney function supports elimination. Macromolecular debris is removed decreasing inflammation and fibrosis	

**Table 3: Principles and effects of compression therapy**

Principles	Rationale	General Effects
<b>Use inelastic compression materials</b>	Inelastic bandages do not have the contractile properties of elastic threading	<ul style="list-style-type: none"> <li>■ Reduced backflow of evacuated lymph</li> <li>■ Reduced production of interstitial fluid via ultrafiltration</li> </ul>
<b>Generate a compression gradient</b>	A single layer bandage cannot generate a gradient on all limb contours, unless the technique of application is adapted. Multiple layers applied systematically and methodically, control fluid formation and return.	<ul style="list-style-type: none"> <li>■ Increased reabsorption of lymphatic loads and excess water</li> <li>■ Improved efficiency of the muscle and joint pumps during movement</li> <li>■ Mechanical softening of lymphostatic fibrosis</li> </ul>
<b>Observe Laplace's Law (P=T/r)</b>	Pressure is directly related to radius. Larger radius receives less pressure when tension is at a constant. Monitor limbs of abnormal contour to avoid entrapment of fluid, skin breakdown and discomfort	
<b>Generate high working pressure, low resting pressure</b>	A "soft cast" prevents constriction and harnesses the muscles and joint pumps, increasing comfort and reducing fibrosis	
<b>Improved quality of life, cosmetic appearance, freedom of movement</b>		

Adapting CDT for the palliative patient: specifics of management when treating with CDT

**Exercise**

Internal forces generated by muscles and joints propel fluid and impact soft tissues. A compression strategy is used during physical activity or structured exercise sessions (table 4).

**Skin care**

Skin hydration and integrity are challenged in the oedematous body regions. CDT compression (elastic or

inelastic) depletes essential oils, creates subtle mechanical stress and may harbour moisture. Girth increases may create odd folds and skin-on-skin contact. Local immune deficits set the stage for cellulitis. Thus vigilant monitoring and techniques aimed at skin preservation is required (table 5).

**Table 4: Principles and effects of exercise**

Principles	Rationale	General Effects (in compression)
<b>Exercise in a compression environment</b>	Exercise increases ultrafiltration, so an increase in interstitial pressure is necessary to control oedema	<ul style="list-style-type: none"> <li>■ Improves uptake and transport of lymph</li> <li>■ Restores and maintains strength, tone and stamina</li> </ul>
<b>Avoid limb deconditioning</b>	Muscle strength and tone increases the efficiency of the anatomical pumps	<ul style="list-style-type: none"> <li>■ Mechanically softens fibrosis</li> <li>■ Increases venous and lymphatic return</li> </ul>
<b>Incorporate deep breathing</b>	Emptying of trunks and ducts, activates diaphragm to assist drainage of peripheral lymphatic territories	
<b>Avoid overstrain</b>	Trauma and inflammation are 'triggers', worsening existing lymphoedema	

**Table 5: Principles and effects of skin care**

Principles	Rationale	General Effects
<b>Restore hydration</b>		<ul style="list-style-type: none"> <li>■ Counteracts mechanical stressors of compression</li> <li>■ Reinforces importance of hygiene</li> </ul>
<b>Maintain hygiene</b>	Restoring the acid mantle using Low pH lotions, decreases microbial count	Educate for early identification of infections
<b>Educate to identify problems</b>		

### Self care education / application

The intensive phase emphasises patient/caregiver education in which the therapist outlines the disease changes and its impact on treatment. Therapists can develop a tailored management plan, which may need adapting to optimise concordance and treatment outcomes. The principles of the plan will include:

- Thorough decongestion and stabilisation of tissues to decrease volume and work burden
- Simplified compression to the most essential level
- Spending consecutive sessions practicing self care
- Emphasising prevention of infection and factors that exacerbate the risk
- Enlisting family or professional support if necessary
- Monitoring success with follow up visits

### Adapting CDT in the palliative patient

#### Set realistic goals

In the palliative patient, CDT may cause discomfort or intense pain, so should be adapted to suit the needs of the patient. While aiming to reduce swelling, the provision of comfort, relief from pain or other swelling related symptoms, and maintaining or restoring function, are desirable and beneficial outcomes. Involving caregivers/ family connects them in deep and meaningful ways, empowers all involved and heals relationships<sup>11</sup>. Early intervention may help prevent or delay lymphorrhoea, markedly swollen and painful limbs and disability.

With failing health, a true distinction between the two phases of CDT may be absent<sup>12</sup>. Intensive compression and MLD both are generally warranted as each provides benefits. In patients with lymphorrhoea, there is an absolute requirement for regular bandage removal, dressing change and reapplication. This demands competent, attentive caregiver administration.

Semi-intensive CDT addresses concerns such as skin integrity, early identification and management of cellulitis, daily observation and adaptation to the advancement of swelling margins, and ongoing pain management strategies. It should be noted that failing health may at some point result in an absolute contraindication to one or more modalities of palliative CDT, therefore regular reassessment is paramount. Nevertheless, when patients and family members realise that the lymphoedema specialist remains ready and unconditionally committed regardless of complications, an air of support, gratitude and hope is maintained.

### Contributions and limitations of CDT modalities

#### Palliative Compression

Obstructive lymphoedema is often resistant to attempts at volume reduction, refilling in minutes following removal of compression. Inelastic bandaging provides containment, effectively arresting the progression of swelling that stretches the skin. With synthetic cotton or foam padding layers, fluid displacement is maintained and successfully counters the sensation of “bursting”. Addressing this single swelling symptom significantly reduces pain and increases comfort. Exudative skin lesions need management input from a wound care specialist. Range of motion is limited or impossible when oedema effectively splints the joints, so reduction can free joints and improve function and mobility.

Elastic compression garments (medically correct gradient support stocking, sleeve, etc), are often uncomfortable due to inherently high resting pressures. If ill-fitting, they can hitch constrict, roll or cord. Sensations of throbbing are common, as is immediate intolerance and exacerbation of pain. Low compression classes of elastic garments may be tolerated, but obstructive lymphoedema overwhelms elastic threads regardless of compression class, and so cannot provide the required containment. Clinicians should be aware of the different types of garments that exist, particularly the difference between circular knit and flat knit garments. Flat knit garments are particularly useful when there is shape distortion or rebound oedema, due to the increased stiffness in these products. Custom-made garments are required if the limb deviates significantly from the normal limb contours. Some patients may choose to remain in inelastic bandages and welcome this relief until the end of life.

#### Palliative manual lymph drainage

MLD can manage swelling and provide an analgesic effect. Since obstructive masses interrupt entire lymphatic quadrants, MLD primarily focuses on creating collateral flow in truncal territories, and secondarily in the limb. Working closely with physicians, optimal pathways can be attended while navigating to avoid superficial and deep tumour lesions. Although volume outcome measures may be difficult to quantify, treatment is essential to address skin tension-related pain, concomitant pain sources, lymphorrhoea, range of motion limitations, and degraded skin integrity. MLD sessions are a rare and welcome extension of compassion, kindness and humane contact. The extension of this service is the most prized aspect of CDT, as the tactile exchange that occurs during MLD forges close bonds between patient and caregiver.

Adapting CDT for the palliative patient: specifics of management when treating with CDT

**Palliative skin care: management of lymphorrhœa**

Excessive skin tension may generate fragile lymph cysts which may rupture under compression, causing copious leakage. Minor abrasions or injuries combined with atrophic changes and dehydration, contribute to further erosion. Dermal infiltrating tumours form non-healing ulcers that progressively worsen. Areas of skin-on-skin contact harbour moisture, fungal and bacterial colonies. Multilayered compression can incorporate absorptive wound dressings, but need to be changed frequently to avoid maceration<sup>13</sup>. Odour control is important; lymphorrhœa and anaerobic bacteria cause patient distress, self-consciousness and loss of dignity. Topical preparations must be incorporated in wound dressings and skin folds to mitigate this and allow patients to engage in social activities. Plastic backings or diapers can contain fluid, lessening saturation of multilayered bandage materials and minimising maceration.

**Remedial exercises**

Normal movement and activity should be encouraged whenever possible. In general, provided that pain control measures are optimised, remedial exercises are gentle enough to be acceptable to patients with advanced illness. However, lymphoedema deep breathing exercises may be a challenge, particularly if dyspnoea is present. Metastatic disease in the bones may lead to a fracture risk even with minimal exercise - the therapist will need to be aware if such a risk exists. Concomitant muscle weakness or paralysis will require more passive rather than active exercises.

**Family support and education**

More so than with conventional CDT, the early involvement of family or a professional caregiver is of importance in palliative CDT. It requires manual application, delivered with precision, understanding and compassion. MLD can be learned quickly when simplified to its essence (for example, single-hand vs. two-handed technique), and with careful mapping, can be sequenced for frequent application between clinic visits, maximising analgesic and fluid resorption benefits. Compression management should never become the responsibility of the patient. Self-removal of a bandage or garment may be impossible, and attempts at re-application could cause dislocation, fracture, skin tears and tourniquets. Constant monitoring of comfort, sensation, capillary perfusion and skin integrity should occur every few hours if the patient is unable to respond.

**Kinesio taping**

Kinesio taping can improve superficial swelling in localised regions (directly beneath the tape) and may be incorporated into the CDT system to promote drainage along anatomical lymphatic pathways. In body regions where MLD is desired but proves difficult to access manually (back, trunk, neck), kinesio taping may be applied, supporting the theoretical premise of increased lymphangioactivity via stretch stimulation. In the palliative patient however, consideration for preservation of fragile skin must over ride kinesio taping, so this modality may be contraindicated. Nevertheless, special techniques for release/removal of the tape while avoiding skin injury may create an opportunity for careful and successful application of this treatment.

**Figure 9: Palliative CDT principles**

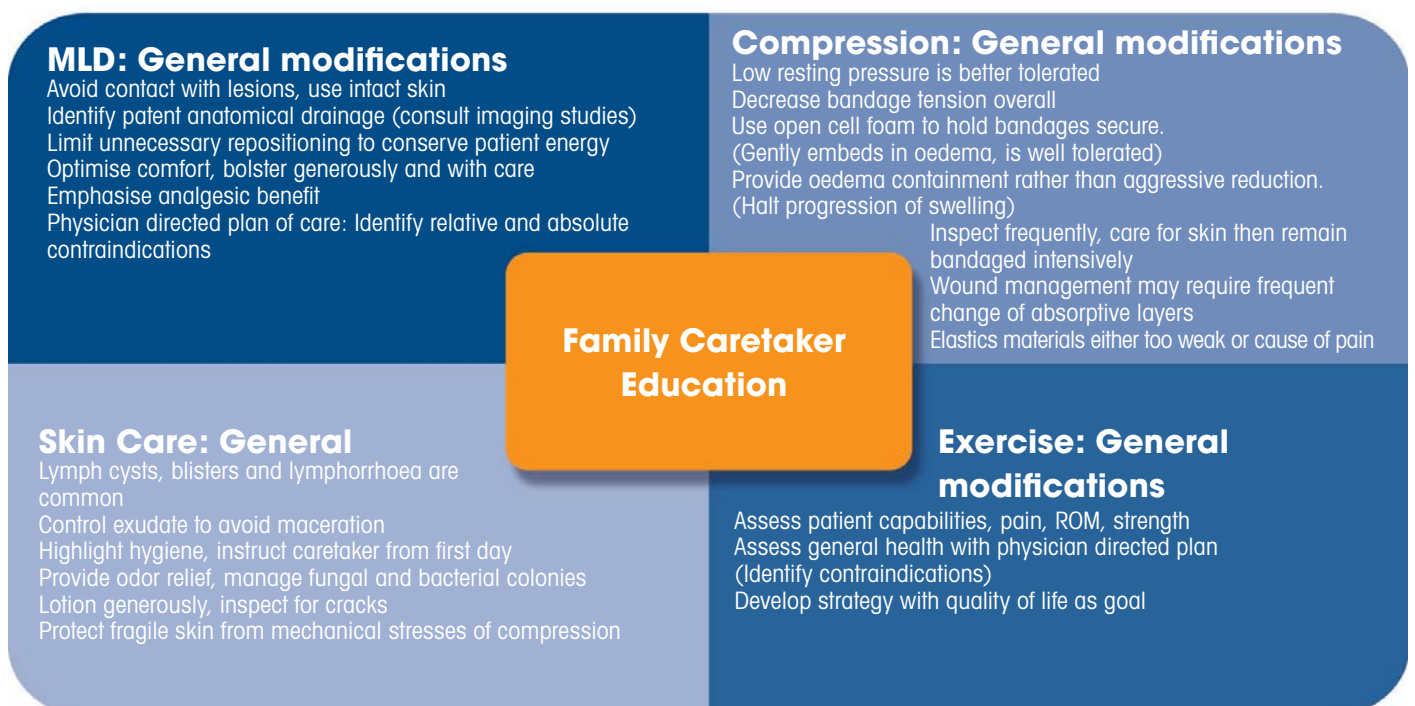




Figure 9 highlights general modifications to the standard CDT approach, and applies broadly to most palliative patients.

### CDT management of oedema in lower body, trunk/upper limbs and of generalised oedema

Treatment strategies adapted to the terminally ill patient may closely resemble those constructed for typical primary and secondary lymphoedema if disease progression is slow, or if oncologic therapy provides periods of disease control. Care plans vary depending upon the extent and location of tumour involvement relative to lymphatic tissues (deep or superficial). Further, renal insufficiency, liver failure, reduced cardiac output and hypoproteinaemia (monitored through serum albumin levels) may constitute relative or absolute contraindications<sup>14</sup>. Tolerance to compression is directly impacted by diabetic, neuropathic, central nervous system disturbances and peripheral vascular complications that may create significant limitations on therapy options.

The presence of relative or absolute contraindications requires particularly close physician directed modifications based upon assessment of drug interactions, severity of any organ failure, and potential interactions or exacerbations created by CDT modalities. Acute congestive heart failure, acute deep vein thrombosis, thrombocytopenia, severe neuropathic or bone pain, advanced peripheral vascular disease (low ABPI), and complications of diabetes may constitute irresolvable challenges.

Intermittent pneumatic compression (IPC) devices are particularly ill-suited in the palliative context because there are almost invariably issues with oedema at the root of the limb, or limbs, which may be made worse with IPC. A medical subcutaneous drainage technique as an alternative to, or in combination with CDT, has been reported in the literature for the treatment of oedema in palliative care and merits further study<sup>15</sup>. This technique uses 'butterfly'-type needles inserted into the subcutaneous space and attached via tubing to a drainage bag. It should be emphasised that this physical drainage has only been applied in the terminal phase and should not be a consideration before this time since it invariably presents risk of infection and/or lymphorrhoea.

### Practical adaptations for lower quadrant oedema

Unilateral lower quadrant oedema commonly advances to both lower limbs as disease progresses to the retroperitoneal nodes. Hypoalbuminaemia (dynamic insufficiency) or physical obstruction (mechanical insufficiency), individually overwhelm lymphatic transport capacity or may combine to create mixed oedema. In general, the therapist could use axilloinguinal collateral pathways (anastomoses) during

MLD, since upper quadrant swelling is rarely triggered during fluid shifting. Diaphragmatic centred breathing drains deep lymphatics including the thoracic duct while neck treatment (supraclavicular fossa, venous angle) supports the central decongestive premise, benefitting the whole lymphatic system.

Compression bandaging may be so effective when applied to mixed or low protein oedema that it may overwhelm proximal territories. Proximal congestion responds to sustained local MLD aimed at emptying the trunk. Compression may be modified to address only one limb segment at a time.

Figures 10 and 11 illustrate specific modifications in CDT approach.

### Dependency

Chronic non-cancer disease states may cause absolute or sustained periods of immobility, generating low-protein, dependent oedema. Since the lymphatic system is largely intact in these cases, MLD treatment of regional nodes with attention to deep lymphatic anatomy (neck and abdomen) can help distal limb oedema. If coupled with limb positioning against gravity (horizontal or elevated) swellings may not require compression.

### Practical adaptations for upper quadrant oedema

As with lower quadrant involvement, upper quadrant modifications are directed by the physician's assessment of disease progression. In general, superficial lymphatic territories (upper or lower) provide current, visual and palpable feedback regarding obstruction of deep structures. In advanced disease non-oedematous quadrants are always at risk since there may be little capacity to receive surplus fluid following collateral drainage with MLD. When the upper quadrant is drained to an ipsilateral lower quadrant, the Stemmer sign is checked daily to gauge capacity to accept more fluid. A treatment plan may be severely limited if there is, for example, severe lymphatic involvement by tumour, subcutaneous tumour, regions of radiation fibrosis, or mixed-aetiology oedema (venous thrombosis, hypoproteinaemia). In these cases one may have to rely largely upon one predominant treatment modality, i.e. only MLD or compression (*Figure 11*).

### Conclusion

Adaptations of standard decongestive therapies in palliative care are possible providing that there is close collaboration with the palliative team in understanding the aetiology of the oedema and a clear visual image of disease location and its impact on standard clearance pathways. The lymphoedema therapist can be an invaluable member of the team who can help improve quality of life by markedly improving physical and psychological comfort.

**Figure 10: Palliative CDT principles**



**Figure 11: Upper quadrant modifications**



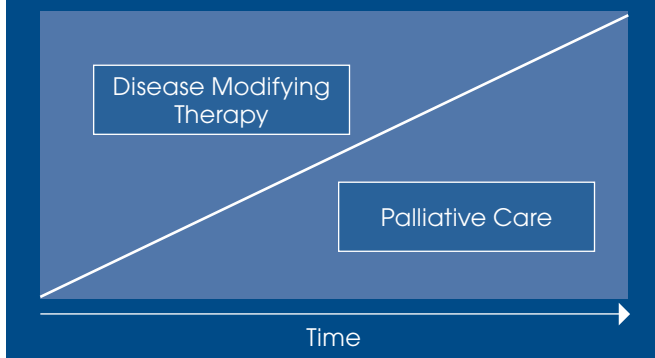
# 5. Symptom control in advanced cancer lymphoedema and oedema at the end of life

Oedema commonly occurs as a consequence of progressive cancer and may be aggravated in the setting of terminal cardiac, renal, hepatic, and pulmonary conditions. Management in the palliative care setting differs from the conventional in several critical ways that must be appreciated to achieve optimal outcomes and clinical success.

## Palliative Care – holistic approach

The broad scope and holistic nature of palliative care can dovetail with oedema treatment. The World Health Organization defines palliative care as *“the active total care of patients whose disease is unresponsive to curative treatment. Control of pain and other symptoms and psychological, social, and spiritual problems are paramount. The goal is best quality of life for patients and their families”*<sup>16</sup>. Uncontrolled oedema poses a threat both to patients’ functional status and quality of life. Palliative care is often conceptualised as being an integral part of comprehensive disease management from the time of diagnosis. However, over time as disease-modifying treatments become fewer and less effective, palliative care plays an ever-increasing role in minimising the burden of illness. Figure 12 conceptually illustrates this approach.

**Figure 12: Palliative care across the disease trajectory**



Key clinical aspects to consider are:

- Pain management
- Psychological support to manage the wide range of psychiatric morbidities that patients may experience at the end stages of illness
- Wound care
- Nutritional support
- Management of bowel and bladder function

Palliative care also address the myriad symptoms that can undermine oedema treatment outcomes, including fatigue, nausea, anorexia, hiccoughs, and dyspnoea. Spiritual support where requested, may be essential as patients reach the terminal stages of illness. Existential and spiritual crises may raise questions of “what’s the point?” or “why bother?” Even the most skilled and devoted lymphoedema therapists will fail if patients’ energy and concerns are consumed by issues of spiritual meaning. The involvement of religious leaders appropriate to a patient’s faith tradition can be an invaluable asset in such situations.

Oedema management is a natural adjunct to this broad range of therapeutic modalities, but cannot be undertaken if adverse symptoms and critical patient needs remain unaddressed. Thus, palliative oedema care should be delivered in conjunction with palliative care, which requires a team approach with a wide range of interdisciplinary expertise. Efforts to control oedema will naturally synergise with those of other clinicians attempting to optimise comfort, function, and psychological well-being.

## Diagnosis

Accurate identification of all the contributing factors to oedema in the terminal phases of illness can be challenging. Cancer is notorious for causing lymphatic damage; patients often sustain lymphatic compromise



from lymph node removal or irradiation<sup>17</sup>. As cancer spreads, it can exogenously compress or infiltrate lymphatics, causing lymphoedema to develop or aggravate established lymphoedema. Thus, lymphoedema should always be in the differential diagnosis for cancer patients with oedema.

Towards the end of life, the precise identification of all the contributing factors to a patient's oedema become moot and irrelevant to management, although one can identify any potentially reversible factors or treatable causes. For example, anticancer therapies, including radiation and chemotherapy, can reduce malignant oedema.

An accurate distinction between lymphoedema and oedema of combined or alternate sources is often neither possible nor necessary. There are many sources of increased ultrafiltration which will lead to fluid accumulation in the interstitium. Principal among these is decreased serum albumin, which may occur due to loss from the kidneys, reduced production in the liver, impaired intestinal absorption, and reduced oral intake with anorexia<sup>18</sup>. Reduced serum albumin lowers the oncotic pressure of the blood plasma and leads to increased fluid leakage through the walls of the blood capillaries<sup>19</sup>.

Increased capillary pressure also increases net ultrafiltrate. Venous return from the extremities may be reduced from cardiac dysfunction, immobility or thrombi. In addition, circulating cytokines such as tumour necrosis factor alpha may render capillaries more permeable and further increase ultrafiltration. Collectively, these may dramatically increase lymphatic load and overwhelm the lymphatic system.

The possibility of an acute venous occlusion should always be borne in mind when working with terminally ill patients. Cancers render patients hypercoagulable and therefore predisposes them to the formation of deep venous thrombi<sup>20</sup>. In addition, many patients have limited mobility and thereby sluggish venous return, further increasing their risk of thrombus formation. Migration of a thrombus into the lungs as a pulmonary embolus may be a fatal event and therefore, even in the palliative setting, thresholds should be low for working up a potential thrombus.

On clinical examination it can be quite challenging, or in fact clinically impossible, to accurately distinguish malignant oedema from an acute deep venous thrombosis. Both can present in an abrupt and rather dramatic fashion; taut, shiny skin with deep pitting may characterise both. Allowing the natural dying process to take its course may be the compassionate and appropriate management option, but this should be discussed with the patient and their family.

### Treatment challenges

One of the greatest challenges in managing oedema in the palliative setting is the absolute necessity of redefining therapeutic success. Generally, we approach lymphoedema patients with the hope of re-establishing "near normal" limb contour and volume. This goal is often untenable for with patients with advanced disease. Therefore, therapeutic goal setting needs to be contextually sensitive and realistic in the degree of autonomy that patients may be able to achieve with oedema management. Goal setting should encompass early caregiver involvement, education, and symptom management. Decelerating the progression of oedema and reducing associated functional morbidity are acceptable palliative goals.

Patients may have dramatically reduced physical capacity. If their illness has compromised neurologic structures, they may be plegic or paretic, and therefore unable to self-bandage or perform remedial exercises. Further, they may be significantly limited by symptoms such as fatigue and dyspnoea due to marked deconditioning. The coordination, dexterity and strength requirements for bandaging and donning compression garments can elude even healthy patients; therefore, these potential difficulties should be greatly respected when formulating management plan for terminally ill patients.

### Pain management

Pain warrants special mention because it is a formidable barrier to effective treatment, degrading to patients' quality of life, and highly prevalent among advanced cancer populations. Cancer pain remains drastically undertreated<sup>21</sup>. Evidence suggests that approximately 40% of ambulatory cancer patients experience inadequately controlled pain and as many as 80% of hospice patients continue to experience high levels of pain<sup>22</sup>. Minority status, female gender, and a history of substance abuse are associated with inadequate pain management. Lymphoedema therapists can play a critical role in empowering their patients to seek appropriate analgesia. In fact, therapists' success may be contingent on patients' proactive solicitation of adequate pain control.

At present, opioid-based analgesia represents the standard of cancer pain management. Societal prejudice against opioids, which is unfortunately prevalent in clinical communities, has been consistently identified as a barrier to patients' receipt of appropriate cancer pain management<sup>23</sup>. Lymphoedema therapists can reassure their patients of the appropriateness of opioid-based analgesia to manage their pain on both a daily basis and prior to oedema therapy sessions.

For many patients, particularly those with wounds, the unwrapping and rewrapping process may incite intense pain. It is critical for therapists, patients and caregivers to

## Symptom control in advanced cancer lymphoedema and oedema at the end of life

appreciate that normal release opioid analgesics require approximately an hour after oral ingestion to reach therapeutic serum levels<sup>24</sup>. Oral transmucosal fentanyl, which can afford meaningful pain relief as soon as seven to ten minutes after ingestion, is the sole exception, and therefore an excellent medication for managing pain associated with oedema treatments.

Non-opioid drug classes play a key role in pain management. Adjuvant analgesics such as tricyclic antidepressants, gabapentin, pregabalin, duloxetine, or carbamazepine all are effective agents against nerve pain. Although most patients' pain can be controlled with oral medications, in the palliative setting patients' limited life expectancies make permanent neural blocks and ablations feasible treatment options<sup>25</sup>. Selective neural destruction may be necessary for patients with extensive neural infiltration by their tumours whose pain cannot be adequately controlled by other means. Pain of this intensity is generally not compatible with effective oedema management and relief must be achieved before considering decongestion.

Working with the local pain team, where available, will ensure appropriate planning for dosage, frequency, titration and review.

### Wound management

An additional challenge is non-healing and potentially highly exudative wounds. Therapists should appreciate that non-healing wounds due to cancerous infiltration of soft tissues are likely to worsen in the absence of effective anticancer therapies. It is therefore critical that therapists incorporate wound management into their oedema treatment programs if wounds are located proximal to or within oedematous tissues (*see section 6 for a comprehensive overview of wound management*).

### Decongestive physiotherapy

There are unequivocal benefits to the delivery of modified complex decongestive physiotherapy (CDP) to patients with oedema or multi-factorial oedema in the palliative setting. CDP reduces skin distention, provides counterstimulation for pain control, limits the accumulation of inflammatory mediators in the interstitium which may sensitise pain receptors and provides a subjective sense of support for the affected body part<sup>26</sup>. Further, reducing the size of an oedematous extremity may dramatically enhance patients' functionality. Many patients are significantly deconditioned or have focal weakness consequent to steroid myopathy or neural pathology. Eliminating cumbersome limb volume can maximise mobility within the constraints of their neural deficits, thereby reducing their risk of immobility-associated problems. Limb volume reduction may be a key factor in allowing patients to remain independent in activities of daily living.

CDP reduces patients' risk of morbid complications<sup>27</sup>. Perhaps most saliently, it reduces the risk of skin breakdown. Tissues in oedematous limbs with boggy and stagnant interstitial fluid have low oxygen saturation and are poorly nourished. CDP may reverse this situation. In addition, by diminishing limb volume and increasing mobility CDP may reduce patients' risk of DVT, further deconditioning, and loss of bone density.

The benefits of CDP to patients' psychological well-being cannot be overemphasised. Patients in the terminal stages of a disease generally experience a strong sense that their bodies and lives have spiralled out of control<sup>28</sup>. Allowing patients to restore semi-normal contour to a oedematous body part can be tremendously empowering. This enhanced perception of control can extend into social, psychological, and functional domains. CDP also provides patients with a constructive focus and offers a unifying goal that they may share with their caregivers. The intimacy of CDP sessions can be tremendously restorative for patients. Unfortunately, 'pulling back' and unavailability of professional caregivers has been well-characterised for terminal patients<sup>29</sup>. CDP offers a neutral and sustained opportunity for patients to share with a caregiver that opposes the general tide of less frequent caregiver contacts. Receiving human touch during manual lymph drainage, particularly over body parts affected by oedema or advanced disease processes, can enhance patients' sense of being accepted, honoured, and cared for.

### Adapting CDP for palliative intent

CDP treatment delivered to patients with terminal illnesses must be humane, and the cost to benefit ratio of all therapeutic elements must be carefully scrutinised. Therapy must be feasible and flexible. Therapists need to approach oedema management in the palliative setting with an appreciation that responsible disease processes are highly dynamic and may progress rapidly. In order to offer patients long-term relief, the oedema maintenance program must have the capacity for equally rapid adaptation. Specific elements of CDP will be addressed in turn.

### Manual lymph drainage

Manual lymph drainage (MLD) remains highly effective in the palliative setting. In addition to its pain-relieving properties and the restorative emotional impact of human touch, MLD can significantly decongest even taut, malignant oedema. Treatments should capitalise on preserved lymphatic anastomoses and drainage routes. To achieve this end, imaging studies can be very helpful as they clarify which nodal pathways may have been infiltrated or exogenously compressed by tumour. Awareness of previously radiated areas is also critical, since superficial lymph pathways in these regions may no longer function. Neural compromise is common in patients with advanced cancers, it is

important to identify any hypaesthetic areas. MLD should avoid areas of dermal compromise, cancerous invasion, extensive fibrosis, or skin hypersensitivity. However, if a trial of MLD over such areas proves beneficial, it should be continued as the overarching goal of palliative care is improved patient comfort and quality of life. Continual adaptation of MLD based on regularly solicited patient feedback is particularly important in the interest of forging a therapeutic bond with patients who have been subjected to frequently painful therapeutic manipulations.

#### Inelastic (short-stretch) bandaging

Conventional multilayer inelastic bandaging can be used in the palliative context<sup>30</sup>. It is important that lymphoedema therapists remain aware of the potential challenges patients may face in achieving an effective compression gradient through self-applied bandaging. As mentioned, restoration of near normal volume and contour of the affected body part may not be possible. In the setting of very limited life expectancy, an elaborate wrapping program, even when effective, may significantly degrade patients' overall quality of life. For this reason, simplicity and expedience are essential. Whenever possible, caregivers should be integrated early on in the management program and encouraged to improvise. Caregivers and lymphoedema therapists may be reluctant to cause patients pain, however it is essential that all involved parties engage actively with the patient to develop strategies for achieving both analgesic and oedema control.

Great caution should be exercised any time an oedematous body part is initially bandaged or when a bandaging strategy is modified. The affected area should be evaluated for neuropathy, dermal compromise, or arterial

insufficiency. Frequent rebandaging in the early stages allows for inspection of the skin and ongoing assessment of patients' responses. Initially copious use of cotton, foam or other types of padding may increase patients' long-term acceptance of bandaging by ensuring their comfort early on in the process.

#### Exercise

Remedial exercises may not be a feasible means of increasing the working pressure of short-stretch bandages in the palliative setting. Many patients' affected extremities are plegic. Cautious incorporation of long-stretch bandages represents a possible means of augmenting the effectiveness of muscle contractions. Also, bandaged limbs may be passively mobilised by both therapists and family members, although the utility of this approach has yet to be established. It is important to identify any sites of significant bone pathology prior to initiating remedial exercises. Of most concern are lesions involving the femoral neck given the propensity of this region to fracture. If patients do have worrisome lesions, isometric muscle contractions can replace conventional remedial exercises. Aerobic activities to stimulate lymphatic return should be encouraged to patient tolerance. Aerobic exercise minimises psychological distress and fatigue among cancer patients, even those with advanced and widely disseminated disease.

#### Conclusion

In conclusion, adapted CDP has the capacity to significantly benefit patients with far advanced disease who have lymphoedema or multi-factorial oedema. CDP can enhance patients' function and comfort while preventing needless complications and enhancing psychological well-being.

# 6. Wound Care

Fungating wounds are commonly associated with metastatic disease, although patients at the end of life can develop wounds such as pressure ulcers or skin tears. Fungating wounds describe malignant cutaneous wounds, fungating tumours, ulcerating malignant wounds and tumour necrosis. They usually occur within the last six months of life<sup>31</sup> and present a challenge to both patients and caregivers. These wounds are often malodorous, highly exudative, friable and disfiguring, causing severe emotional distress and isolation at a time when patients need social and family support the most.

A retrospective analysis of the tumour registry in the United States<sup>32</sup> demonstrated that malignant cutaneous lesions occur in 5% of patients with cancer and 10.4% of patients with metastatic disease. Cutaneous malignancies may be primary (melanoma, squamous cell, basal cell or cutaneous T-cell lymphoma) or they may be secondary to local spread from a primary tumour. Table 6 lists the common sites of metastases.

Clinical management challenges are related to tumour pathophysiology. The rapid growth of the tumour often

**Figure 13:**  
Fungating  
tumour  
secondary  
to breast  
cancer



outstrips its blood supply, leading to tissue hypoxia and necrosis. The highly exudating, fungating tumour extends above the level of surrounding skin, or as ulcerating erosions with a necrotic base that bleed easily and become ideal sites for bacterial growth (figure 13). Often the chronic inflammation is manifested as erythema, induration, and fragility in the surrounding skin which is difficult to distinguish from infection. Heavy exudate also leads to maceration of the surrounding skin.

## Assessment and management

### Assessment

Because the goal of care is not always to heal the wound, assessment of symptoms, quality of life and pain are of primary importance, with wound assessment as secondary. There are a number of wound assessment tools available, but in any case, the patient, wound and environment should always be considered. The MEASURE conceptual framework<sup>34</sup> for example, considers:

*Measure* - length, width, depth, area of wound

*Exudate* - amount, quality

*Appearance* – of wound bed, tissue type, amount

*Suffering* - pain level using validated pain scale

*Undermining* - present or absent

*Re-evaluate* - monitor all parameters on regular basis

*Edge* - condition of wound edge and surrounding skin

**Table 6: Common sites of metastasis to the skin<sup>33</sup>**

Primary	Metastatic site to skin
Lung and breast	Head, neck, anterior chest
Gastrointestinal	Upper abdominal wall
Genitourinary	Lower abdominal wall, external genitalia
Stomach	Umbilicus
Melanoma	Extremities
Oral Cavity	Face



# Wound Care

In malignant cutaneous wounds, certain parameters may be of lesser importance. While wound size will rarely decrease, it is an important indicator of disease progression. Similarly, while an advancing border of epithelium is unlikely, monitoring the extent of maceration and induration will determine the response to management.

**Management:**

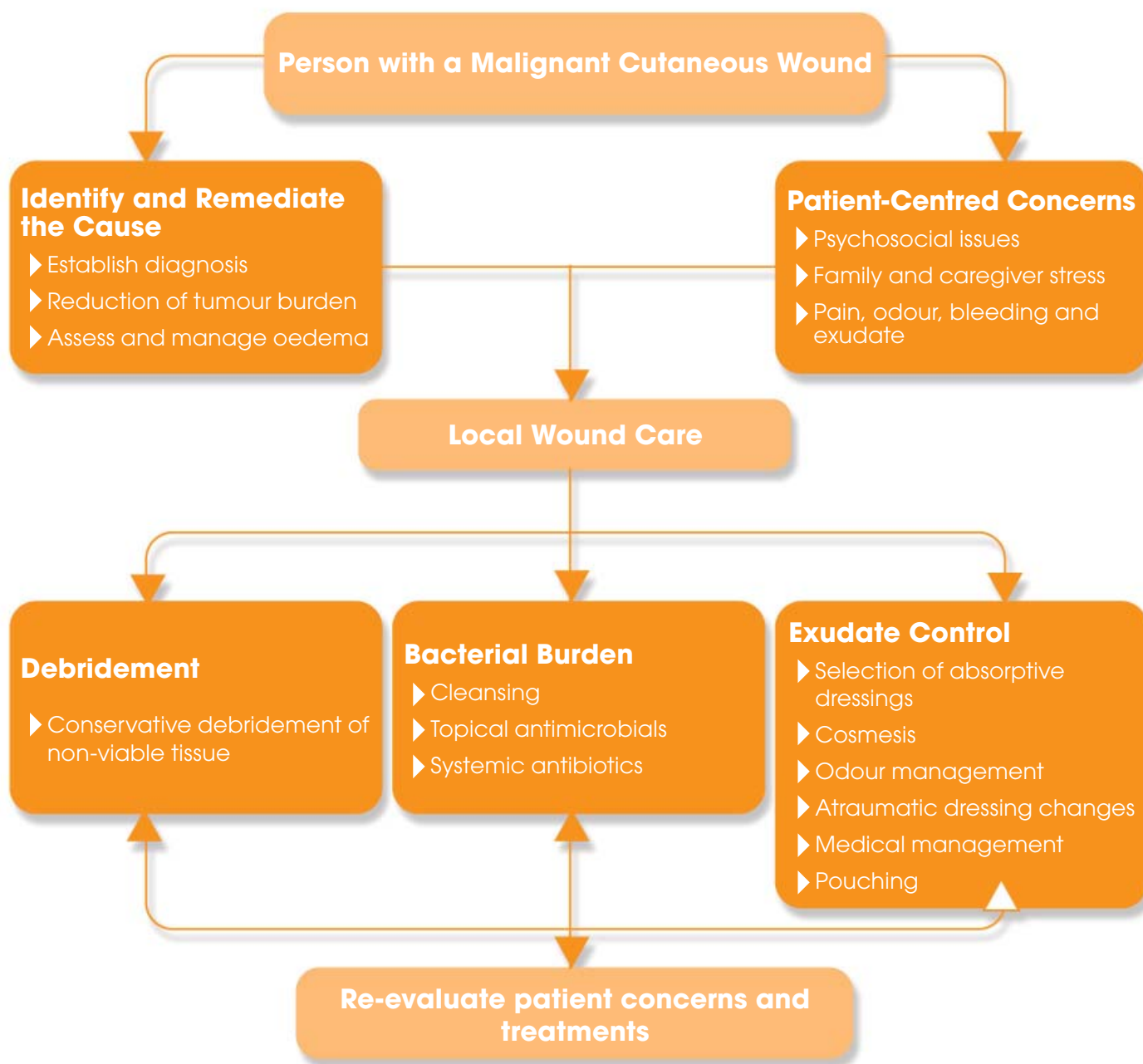
Healing is an extremely unlikely outcome with fungating wounds, so the aim is symptom and patient management. Using an algorithm to determine clinical decision making can be invaluable (figure 14).

**Identifying and remediating the cause**

Not all cutaneous skin ulcers in persons living with malignancy are malignant. Venous stasis ulcers, neuropathic diabetic foot ulcers, pressure ulcers and inflammatory ulcers occur. These may be 'healable', which can improve quality of life.

Malignant cutaneous wounds often present as indurated tender subcutaneous nodules. Infiltration of the skin and localised oedema may produce the typical peau d'orange appearance and overlying skin will be feathered down to the subcutaneous tissues. In time these nodules may

**Figure 14: Pathway for the assessment and management of cutaneous malignant wounds<sup>35</sup>**



## Wound Care

ulcerate. A biopsy will establish diagnosis and therefore guide management which can include a short course of chemotherapy, radiation, or surgical reduction of tumour bulk.

Increased vascular permeability and rapid angiogenesis often lead to altered lymphatic drainage and accumulation of oedema in the tissue surrounding the wound. The primary tumour or its treatment may lead to generalised oedema in the area.

### Addressing patient-centred concerns

Here, both the disease and the illness experience of the patient are considered. The disease is established through history, physical examination and appropriate investigations. Psychosocial factors such as body image, depression, embarrassment, guilt, denial, anger, isolation, intimacy and self respect must be explored with the patient. These, along with the environment, guide the care plan, which is determined with the patient where possible.

The four most common symptoms of concern are:

- **Exudate** - May be high due to neovascularisation, increased permeability of the vascular membrane, increased proteolytic activity and often, bacterial load
- **Odour** - Primarily related to bacterial burden, particularly anaerobic species such as bacteroides. Management includes removal of non-viable tissue, decreasing bacterial loads using topical metronidazole or anti-microbial and charcoal dressings, kitty litter or charcoal in the room, odour removing sprays
- **Bleeding** - Tumours have exuberant capillaries which are fragile and friable. The main cause of bleeding is traumatic dressing changes so, techniques to minimise this, along with atraumatic dressings are required (*figure 15*). Bleeding can be managed by applying gentle pressure for at least 15 minutes, or if ineffective, a calcium alginate dressing. Absorbable dressings containing purified gelatin, collagen or oxidised regenerated cellulose plus collagen also have haemostatic properties. More aggressive bleeding may require cautery or electrocautery, operative tying or embolisation of bleeding vessels, or radiotherapy. Tumours near vital arteries have the potential to erode into the artery with fatal consequences – this should be acknowledged in the care plan
- **Pain** - The World Union of Wound Healing Societies has published a consensus statement on assessing and managing wound related pain<sup>36</sup>. Wound

related pain is subdivided into the following:

- ▶ **Background pain**; persistent or intermittent underlying pain felt when no wound manipulation is taking place. It may be related to the underlying cause of the wound or local wound factors such as ischaemia or infection
- ▶ **Incident (breakthrough) pain**; occurs during movement or with dressing slippage
- ▶ **Procedural pain**; results from dressing removal, cleansing or dressing application
- ▶ **Operative pain**; associated with any intervention that would normally require an anaesthetic (local or general) to manage pain, for example, debridement. Non-pharmacologic interventions can also be employed. Such strategies involve moving the locus of control to the patient by employing the 'stop rule' and allowing them to choose interventions such as hand holding, warm blankets and guided imagery

Psychosocial and environmental factors such as age, gender, educational level, environment and previous pain history can all influence patients' experience of pain. Pain history and current pain level can be assessed using a Visual Analogue Scale or Wong Baker Faces Scale and identify pain characteristics (nociceptive, neuropathic or combination type), and thus guide pharmacologic management.

Background pain can be reduced by using occlusive dressings and those containing analgesics, for example ibuprofen, to maintain a moist, physiologic environment at the wound bed. Narcotic solutions mixed with a hydrogel and applied to the wound bed to control background pain.

Procedural pain related to dressing changes can be reduced by using atraumatic dressings and those which reduce the frequency of dressing changes. It is important that the patient feels in control of the dressing change in order to help minimise pain and anxiety. Dressings should be removed gently and 'time-out' breaks taken if necessary. Showering or soaking the dressing with saline or water may help. Systemic narcotics given approximately one hour before dressing change can help to reduce both anticipatory and interventional pain. In the author's hospital palliative care unit, a protocol using



**Figure 15:**  
Squamous cell carcinoma on the lower limb

## Wound Care

sub-lingual fentanyl is used for severe pain related to dressing changes. The fentanyl is titrated up at 20 minute intervals to a maximum of three doses until the patient is drowsy but awake. Respiration and oxygen saturation are monitored.

### Wound debridement

Removal of devitalised tissue is important in managing odour and bacterial burden. Methods include:

- **Autolytic:** Here, the body's own proteolytic enzymes breakdown non-viable tissue using dressings such as moisture donating hydrogels under a semi-occlusive dressing, and alginate or hydrofibre dressings for heavily exuding wounds. It is a slow process, and can increase odour through growth of anaerobic species in the wound
- **Enzymatic:** Exogenous proteolytic enzymes such as collagens are applied to the wound bed after cleansing
- **Mechanical:** Here, mechanical forces such as irrigation, debride the wound. Pressure should be

in accordance with the friability of the wound

- **Conservative sharp debridement:** Uses forceps, scissors or scalpels to remove non-viable tissue. This method is fast and effective but requires the clinician to have the necessary skill and may require local anaesthetic or non pharmacologic approaches to control pain
- **Surgical debridement:** Aggressive debridement to reduce tumour bulk or to control bleeding - requires a general anaesthetic in the operating theatre
- **Biological debridement:** Maggot therapy, seldom used in fungating wounds

### Managing Bacterial Burden

In malignant wounds, devitalised tissue and the compromised host defences increase the risk of infection. Infection may be difficult to distinguish from chronic inflammation, especially in malignant wounds which have an inflammatory component. Table 7 outlines the defining criteria and intervention for infection ([www.woundinfection-institute.com](http://www.woundinfection-institute.com))

**Table 7: Bacterial Burden in Chronic Wounds ([www.woundinfection-institute.com](http://www.woundinfection-institute.com))<sup>37</sup>**

Term	Clinical Interpretation	Intervention
<b>Contaminated</b>	Bacteria on surface only - no signs or symptoms	None
<b>Colonised</b>	Bacteria attached to surface, starting to form colonies, minimally invasive. No local tissue damage	None
<b>Localised infection (critical colonisation or occult infection)</b>	Bacteria more deeply invasive. Local wound bed involved. Healing compromised in healable wounds. Signs of infection may be present: <ul style="list-style-type: none"> <li>■ friable bright red granulation tissue</li> <li>■ increased or altered exudate</li> <li>■ increased odour</li> <li>■ increased pain</li> <li>■ localised oedema</li> </ul>	Manage with topical antimicrobials or antimicrobial dressings and debridement
<b>Spreading infection</b>	Surrounding tissue involvement. In addition to the subtle signs described above, classic signs of infection such as pain redness, heat and swelling may be present. Other signs and symptoms include: <ul style="list-style-type: none"> <li>■ wound breakdown with satellite lesions</li> <li>■ induration and redness extending well beyond the wound borders</li> <li>■ lymphangitis</li> <li>■ general malaise</li> </ul>	Manage with topical antimicrobials or antimicrobial dressings and debridement
<b>Systemic infection</b>	Classic signs; pyrexia or hypothermia, tachycardia, tachypnoea, elevated or depressed white cell count and in more severe cases, multi-organ system failure	As for spreading infection. Other sources of infection need to be eliminated Systemic and topical measures required

# Wound Care

## Biofilms

Biofilms occur when bacteria attach to a surface and change their phenotypic expression from the free planktonic form to the sessile form, where genes that produce polysaccharides are upregulated. More bacteria are recruited and eventually through cell to cell signalling, a critical number is achieved (quorum sensing) which triggers differentiation into a mature biofilm<sup>38</sup>. The sessile bacteria in biofilms are significantly more difficult to eradicate than planktonic bacteria because they are protected by the polysaccharide matrix, and some have downregulated their metabolism, making most traditional biocides ineffective. There is some evidence that iodine containing dressings may be effective against bacteria in biofilms, but currently, the 'debride-and-cover' approach, where the wound is debrided and covered with a dressing containing either silver or iodine is the most effective.

Other strategies to control the bacterial burden of the wound include the use of antiseptic irrigating fluids at dressing changes, good debridement of non-viable tissue including necrotic slough from the surface, and the use of dressing products containing antimicrobial products. There is debate within the literature surrounding the use of topical antiseptic solutions for wound irrigation, as most are toxic to granulation tissue in vitro. However, there is consensus that the targeted use of antiseptic solutions for managing bacterial loads which are of greater concern than stimulating healing is appropriate. Povidone iodine and chlorhexidine may be useful in controlling bacterial loads in malignant wounds and are usually well tolerated by patients. Other antiseptic solutions include:

- **Sodium hypochlorite solution:** Dakins solution and Edinburgh University Solution of Lime (Eusol) (buffered preparation) can select out Gram negative micro-organisms. High pH causes irritation to skin
- **Hydrogen peroxide:** Effervesces on contact with wound bed which causes desloughing. Can harm healthy granulation tissue and may form air emboli if packed in deep sinuses
- **Chlorhexidine:** Active against Gram positive and negative organisms, with small effect on tissue
- **Acetic acid (0.5% to 5%):** Low pH, effective against *Pseudomonas* species, may select out *S aureus*
- **Povidone iodine:** Broad spectrum of activity, although decreased in the presence of pus or exudate. Toxic with prolonged use or over large areas

Antimicrobial dressings such as medicated tulle dressings, silver containing dressings, iodine preparations, polyhexamethylene biguanide dressings, hypertonic saline and honey preparations are also effective. Such dressings

have varying properties and modes of action, as outlined in table 8.

## Exudate Control

Exudate may be controlled through appropriate debridement, management of bacterial load, dressing selection and medical intervention.

## Dressing Selection

In malignant cutaneous wounds, the goals of dressing selection include:

- Exudate management
- Atraumatic removal and application
- Odour control
- Control of bacterial burden
- Minimum dressing changes
- Control of bleeding
- A cosmetically pleasing appearance
- Maintenance of function

For the patient with a fungating wound, exudate and odour management are important both on a practical and psychological level. There is a plethora of dressings that will manage these symptoms, so in order to determine the most appropriate for the patients, liaison with a wound care specialist (where available) and the patient is required. Here, a brief summary of dressing classifications is given.

- **Non-adherent dressings:** allow exudate to flow through into a secondary dressing and can be left in place for up to one week, thus reducing trauma and pain associated with dressing changes
- **Alginates:** absorb moderate amounts of exudate, help control bleeding and promote autolytic debridement. They are conformable and may also contain antimicrobials such as silver to help manage bacterial load
- **Hydrophilic fibre dressings:** absorb moderate amounts of exudate and are very conformable. May contain silver and help promote autolytic debridement
- **Absorbent foams:** absorb moderate amounts of exudate; may be adhesive or non-adhesive and may have a non-adherent contact layer. May also contain silver and polyhexamethylene biguanide to control bacterial burden, or ibuprofen to manage wound related pain. May cause maceration
- **Hydrogels:** gels or solid sheets containing high water content - useful for dry wound beds to reduce pain and promote autolytic debridement. The gels can be used to deliver medication to the wound bed; some formulations contain silver



# Wound Care

**Table 8: Antimicrobial Dressings**

Antimicrobial Agent	Dressing Forms	Comments
<b>Medicated tulle</b>	<p>Petrolatum gauze or other non adherent vehicles impregnated with:</p> <ul style="list-style-type: none"> <li>Antibiotics (framycetin, fucidic acid, bacitracin zinc)</li> <li>Antiseptics (chlorhexidene, iodine)</li> </ul>	<ul style="list-style-type: none"> <li>Bacterial resistance may develop</li> <li>Antibiotics may cause irritation or allergy</li> </ul>
<b>Silver dressings</b>	<p>Vehicles may include:</p> <ul style="list-style-type: none"> <li>Alginates</li> <li>Foams,</li> <li>Hydrophilic fibres</li> <li>Gels</li> <li>Powders.</li> <li>Impregnated gauze</li> <li>Combined with oxidised regenerated cellulose/collagen</li> <li>Combined with collagen</li> <li>Coated polyethylene mesh</li> <li>Impregnated hydrocolloids</li> <li>Combined with charcoal in a sachet</li> </ul>	<ul style="list-style-type: none"> <li>Silver may be atomic or ionic form</li> <li>Broad spectrum of activity against bacteria</li> <li>Debate on effectiveness of high vs. low release formulations</li> <li>Some formulations kill bacteria within dressing</li> <li>May reduce inflammation through reduction in MMP's</li> <li>May be useful against biofilms in a 'debride-and-cover' strategy</li> <li>Charcoal in preparation can control odour</li> <li>Choose vehicle depending on other wound characteristics</li> </ul>
<b>Iodine</b>	<p>Three preparations:</p> <ul style="list-style-type: none"> <li>Iodophor impregnated gauze</li> <li>Slow release molecular iodine in cadexomer starch beads</li> <li>Povidone iodine impregnated non-adherent dressing</li> </ul>	<ul style="list-style-type: none"> <li>Broad spectrum activity against gram negative, gram positive, anaerobes, viruses and fungi</li> <li>Some evidence of effectiveness of the cadexomer form against biofilms - all may be useful in the 'debride-and-cover' strategy</li> <li>Cadexomer starch absorbs wound fluid (6x weight)</li> <li>Care with large amounts over long periods due to possible thyroid interaction</li> </ul>
<b>Polyhexamethylene biguanide</b>	<p>Multiple preparations</p> <ul style="list-style-type: none"> <li>Ribbon gauze</li> <li>Gauze squares</li> <li>Transfer foam</li> <li>Backed foam</li> <li>Non-adherent</li> </ul>	<ul style="list-style-type: none"> <li>Broad spectrum of activity</li> <li>Bacterial kill largely in dressing</li> <li>Choose vehicle based on wound characteristics</li> <li>Ribbon gauze useful for sinuses</li> </ul>
<b>Hypertonic saline</b>	<p>Hypertonic saline in</p> <ul style="list-style-type: none"> <li>Gauze</li> <li>Gel</li> </ul>	<ul style="list-style-type: none"> <li>Help to debride necrotic tissue</li> <li>Help to control bacterial loads</li> <li>May be painful</li> </ul>
<b>Honey</b>	<p>Leptospermum honey in</p> <ul style="list-style-type: none"> <li>Liquid form</li> <li>Alginate pads</li> <li>Hydrocolloids</li> </ul>	<ul style="list-style-type: none"> <li>Biocidal effect is multifactorial</li> <li>May assist with autolytic debridement</li> <li>Choose formulation based on wound characteristics</li> </ul>

## Wound Care

- **Absorbent Pads:** can absorb large amounts of drainage
- **Gauze:** to be used in combination with a non-adherent contact layer gauze not directly onto the wound bed
- **Barrier films and ointments:** in the form of an acrylate barrier, or may contain dimethicone, zinc oxide or petrolatum - useful to help protect the peri-wound skin from maceration
- **Ostomy products:** high volume enterocutaneous fistulae can be managed by pouching with ostomy products. A skilled enterostomal therapist should be consulted where possible

### Medical and surgical management

If exudate remains problematic, a targeted course of chemotherapy may help to reduce tumour bulk and control drainage, as can conservative surgical tumour debulking. If it is felt that the exudate is more inflammatory in nature and less related to bacterial burden, a short course of a topical steroid can be tried. Steroids should be carried in either cream or solution formulations as ointments will not mix with exudate.

### Re-evaluation

For patients whose wounds are unlikely to heal or for whom healing is not the priority of care, non-healing endpoints such as exudate control, odour management, preventing infection, and pain relief should be used as prognostic indicators of improvement. Care plans should be reviewed regularly, particularly if there is change in the status of the wound or the patient.

### Conclusion

Fungating wounds are a constant visible reminder to the patient of their disease process. Excessive drainage, odour and significantly interfere with the quality of life and often lead to isolation from family and social support when this is needed most. By using the pathway to assessment and treatment, the caregiver can reduce symptoms for patients living with fungating wounds.

Figure 16: Summary Algorithm



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# 8. Glossary

## **Cellulitis**

An acute bacterial infection presenting as a febrile illness with systemic upset which often precedes the development of redness, pain, swelling and warmth in the affected lymphoedematous area

## **Complete decongestive physiotherapy/therapy (CDP/CDT)**

Comprises 4 elements of therapy to manage lymphoedema;

- Compression (bandages or garments)
- Manual Lymphatic drainage
- Exercises
- Skin care

## **Cor pulmonale**

Right-sided heart failure

## **Fibrosis**

Thickening of the skin and underlying structures due to the inefficient drainage and build-up of protein-rich lymph fluid

## **Kinesiotaping**

Kinesiotaping involves the application of narrow strips of elastic tape to the affected area. It is thought to improve muscle function and lymph flow

## **Lymphoedema**

Swelling (generally of limbs) due to the accumulation fluid in the interstitial tissue as a result of lymphatic system failure

## **lymphorrhoea**

Leakage of lymph fluid from vesicals

## **Manual lymphatic drainage**

Massage-like manipulation of the affected area following the direction on lymph flow to stimulate lymph movement

## **Papillomatosis**

Pouching of pockets of skin between fibrosed areas

## **Secondary lymphoedema**

Lymphoedema resulting from removal or damage to lymph nodes (for example, after surgery), fibrosis of the nodes (post-radiotherapy) and injury or infection

## **Stemmer sign**

Inability to pinch a fold of skin at the base of the second toe



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# The ILF Objective :

## To improve the management of lymphoedema and related disorders worldwide

- To increase **awareness** by raising the profile of lymphoedema.
- To increase **knowledge** about lymphoedema by initiating and/or contributing to **Research Programmes**.
- To **disseminate** this knowledge by implementing an **international, not-for-profit, publications strategy**.
- To increase **understanding** of lymphoedema and its management by creating and/or contributing to the development of **Education Programmes**.
- To provide a cross cultural networking platform through an **Annual International Event** where all stakeholders will have the opportunity to contribute and influence the ILF agenda.
- To promote and document Best Practice with the development of an **International Minimum Dataset**.
- To facilitate and/or contribute to better **access to treatment** for patients worldwide.
- To promote and **support initiatives** whose goals are to improve the national/regional/local management of lymphoedema anywhere in the world.
- To help the Healthcare Industry understand the **real needs** of patients and practitioners, and develop and evaluate improved diagnostic tools and treatments.

