Introduction
This fact sheet has been produced as a resource for healthcare professionals and aims to help determine the best possible approach to managing oedema in advanced ill health. The information has been written with particular thought for people with advanced cancer in whom oedema is a common problem. However, the principles can also be applied to people with other advanced illness. It should be shared with the medical team caring for the patient as they may wish to discuss other treatment approaches specific to the particular illness.

Oedema can be one of the most distressing symptoms affecting patients with advanced ill health. Although most commonly occurring in the limbs, it can also affect the trunk, genitalia, head and neck. It may lead to immobility, pain and discomfort, loss of function, leakage of fluid from affected areas, cellulitis, altered body image, sexual difficulties, anxiety and depression.

Trying to accurately determine the underlying cause will ensure optimal success but acknowledging the impact of oedema on the patient is paramount to help identify the best approach in managing the condition and its associated features.

Establish the patient’s priorities:
- How much of a priority is the oedema, in the context of what is happening to the patient?
- Consider the likely causes. What are their other priorities?
- Is it likely to become more of a problem over time, such that effective management now may help to prevent worsening?
- Where is the patient in the context of the underlying illness? e.g. How advanced is it and are there further disease modifying treatments possible and acceptable to the patient?
- How you assess and manage the patient will depend very much on what the patient feels is important and their ability to cope with the treatment process. Even with an advanced illness, optimal management of oedema may still be appropriate.

Causes of oedema
Under normal physiological conditions, there is a net filtration of fluid out of the blood capillaries into tissues.

Oedema is the accumulation of excess fluid in the interstitial space of the tissues and occurs whenever the fluid filtration rate exceeds lymphatic drainage.

Factors affecting net capillary filtration
- Increased Venous Pressure
  - Right Heart Failure
  - Venous occlusion or compression
  - Salt/water retention
  - Chronic Venous stasis/dependency syndrome
- Inflammation
  - Infection (cellulitis)
  - Tissue injury/tumour infiltration
  - Dermatitis e.g. rosacea and non-infective forms of inflammation e.g. granulomatous disease (Crohn’s)
- Reduced plasma colloid osmotic pressure
  - Hypoalbuminaemia

Factors affecting lymphatic drainage
- Damage or blockage to lymphatics
  - Surgery, radiotherapy, tumour
- Reduced function of lymphatics
  - Congenital/genetic lymphatic anomalies
  - Immobility/reduced muscle pump
  - Overload and exhaustion of lymphatics from sustained high microvascular fluid filtration
  - Obesity

Identifying the factors involved is important when tailoring the approach to management.

Assessment
Features of oedema:
Assessment of oedema should include a thorough medical history (including development of oedema) and examination including:
- Speed of onset and duration
- Appearance of the skin (colour, temperature, integrity)
- Distribution/extent of oedema. (Including head and neck, truncal, genital oedema)
Palpation of tissues including pitting
Associated symptoms (pain, sensory changes, breathlessness)
Medication (side effects)
Additional complications (e.g. fungating lesions, lymphorrhoea, neurological deficit)

Some features indicate the need for urgent investigation or treatment.
Sudden onset or worsening of oedema – consider:

- **Superior Vena Cava Obstruction (SVCO)**
  (Bilateral arm oedema, facial oedema, headache, breathlessness, distended veins over neck/chest)
- **Inferior Vena Cava Obstruction (IVCO)**
  (Bilateral leg oedema with truncal/genital oedema, distended veins over abdomen)
- **Venous Thrombosis** (Upper or lower limb. Especially if unilateral. May be painful or tender, dusky colour, distended veins)
- **Heart Failure** (Very soft pitting, breathlessness lying flat)
- **Cellulitis** (Erythema may be diffuse, increased skin temperature, may have pain and may be systemically unwell)

Other features

- **Chronic vena cava obstruction/compression**. The onset of oedema may be more gradual, but with collateral circulation, distended veins may be more prominent.
- **Presence of enlarged lymph nodes**. Consider recurrent cancer or infection.
- **Venous incompetence**. In chronic oedema of venous origin, the distal limb often has a dusky hue and distended varicose veins which resolve on elevation. Thread veins may occur particularly around the ankle.
- **Dependency/gravitational oedema**. This tends to start as soft pitting oedema of the lower legs, often associated with reduced mobility.
- **Local malignancy**. This may present as demarcated lesions in the skin with raised edges or satellite lesions. These may advance rapidly and may ulcerate.

Further investigations

- **Ultrasound/CT scan**: Indications: – if DVT suspected, or progressing lymphadenopathy, or hepatomegaly leading to venous or lymphatic obstruction.
- **Blood tests**: FBC, U&Es (renal impairment), Albumin, D-dimers (don’t be misled: False positives are common, false negatives can occur).
- **ECG/ proBNP /Echo**: If heart failure is suspected.

**Management of oedema**

1) **Emergency situations**
The initial focus of treatment is on addressing emergency or potentially urgent situations. Immediate liaison with medical colleagues is usually required e.g.

2) **Reverse the reversible**
The next priority is to consider any non-urgent factors which are potentially reversible. The focus is on the patient’s own priorities and on ensuring that the benefits of treatment are not outweighed by the burdens e.g.

- Advancing cancer/recurrent malignancy – referral for palliative anticancer treatment where appropriate e.g. radiotherapy, chemotherapy or hormone treatment. If tumour is compressing or blocking peripheral lymphatic/venous drainage, consider dexamethasone (6-12mg daily PO for a 5-7 day trial titrating down after an initial response or stopping if no response).
- **Anaemia** – in anaemia of chronic disease consider treatment by blood transfusion, consider oral or intravenous iron therapy in cases of iron deficiency anaemia and replace other haematinics if vitamin B12 or folate deficiency.
- Fluid-retaining drugs (e.g. NSAIDs & corticosteroids) exacerbate oedema – consider reducing dose or discontinuing where possible. (Other drugs that may aggravate oedema include calcium channel blockers and gabapentin/pregabalin.)
- **Heart failure** – may respond to conventional treatment (e.g. diuretics, ACE-inhibitors etc).
- **Malignant ascites** – reduction of ascites (e.g. through anticancer therapy, paracentesis, diuretic therapy) may also improve associated oedema.

3) **Tailor treatment options**
The focus of management is on skin care, limb positioning and support, exercise, lymphatic drainage and compression. The Lymphoedema Support Network has produced a number of other useful fact sheets on these areas which, whilst targeted at lymphoedema, are equally applicable to other forms of oedema. Skin care and limb positioning can be undertaken in all cases,
whilst the introduction of the other components of care needs to be considered in the context of the patient's condition and the underlying causes of the patient's oedema.

**Skin care**
Effective skin care in the form of daily moisturising and careful attention to hygiene optimises skin condition and minimises the risk of skin problems which can lead to infection/cellulitis.

**Limb positioning and support**
Elevation of the affected limb, where possible to just above the level of the heart, reduces oedema by promoting venous return which lowers lymph load. Appropriate positioning and support of a swollen limb (e.g. by using pillows when the patient is lying in bed) can improve comfort in a very ill person.

**Exercise, movement and function**
Activity stimulates lymphatic and venous drainage and promotes mobility and function in the affected limb. The focus is on tailoring activity to the patient's needs, ability, general health and disease status. The site of the swelling should be considered, together with the underlying cause of the oedema (particularly in the case of obstructive oedema, where specialist advice on appropriate exercise should be sought). Where a person is unable to actively move a limb, passive movements can also be helpful.

**Lymphatic drainage**
Lymphatic drainage, or massage, assists in managing oedema and providing comfort by promoting lymph flow from congested areas and protein removal from the tissues. There are two main recognised forms of massage in lymphoedema management, both incorporating deep breathing techniques:

- **Manual Lymphatic Drainage (MLD)** is a gentle, but highly specialised technique, undertaken by trained and accredited practitioners.
- **Self Lymphatic Drainage (SLD)** is a simplified version of MLD that patients, relatives/carers and healthcare professionals can be taught by a trained therapist.

**Compression**
Compression, through the use of bandaging, compression hosiery or adjustable Velcro® compression devices, plays an important role in reducing and controlling swelling. External support, particularly when combined with muscular activity, stimulates lymphatic and venous drainage and will also often bring comfort to a swollen limb. It may not always be appropriate in advanced disease (particularly if there is severe hypoalbuminaemia, because fluid can shift proximally or if there is arterial insufficiency or uncontrolled heart failure. Compression should be measured and fitted following assessment by an appropriately trained professional, as inappropriate or ill-fitting compression may lead to a deterioration of the oedema and skin condition.

**Lymphoedema management**
Where true ‘lymphoedema’ is identified (with evidence of firm, thickened or fibrotic tissues), refer to a specialist service for further assessment of the patient’s lymphoedema and review of appropriate management options. These are determined by the site, stage, severity and complexity of the swelling, and require the input of a trained practitioner.

4) **Additional treatments**

- **Intermittent pneumatic compression pumps**
Pneumatic compression pumps can have a role in managing oedema in advanced disease. They should only be used by an appropriately trained healthcare professional.

- **Diuretics**
Have no effect in uncomplicated lymphoedema; however, can be considered if there is midline, genital or head and neck oedema, if there are signs of associated heart failure, IVCO, hypoproteinaemia or associated ascites of central origin. Consider Spironolactone 25-100mg/day together with a loop diuretic such as Furosemide, dependent on kidney function.

- **Taping**
The application of sports tape can help alleviate pain and may facilitate lymphatic drainage by lifting the skin. It is particularly beneficial in the reduction of trunk, head and neck lymphoedema where compression hosiery or bandaging is difficult or not appropriate. Sports tape should only be applied by professionals with the appropriate level of training.

5) **Communication/Emotional support**
It is important to recognise and acknowledge the distress and concerns that oedema can cause.

It can often serve as a very visible reminder of the illness that a person is facing. It may be the focus of someone’s anxiety or depression.

Explanation of underlying causes and treatment options may help to reduce anxiety and develop shared realistic goals.

- **Give opportunity to discuss areas of concern**
- **Enquire specifically about the impact of the oedema, physically and emotionally**
- **Explore their understanding** of the life-threatening nature of their condition
- **Acknowledge uncertainties** and give options where possible
- **Denial** may be an effective coping strategy for many people. It may even appear that a person hasn’t been told or heard what has been said. Seek their views (verbal and non-verbal clues) e.g. “Are you the sort of person who likes to know what is going on?”
- **Involves other members of the multi-professional team** where appropriate e.g. Specialist Palliative Care Services / Macmillan Nurses, Physiotherapists, Occupational Therapists, Social workers, Chaplains, Psychologists
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