Rehabilitation Care Pathway
Lymphoedema
This pathway is for patients with cancer related lymphoedema. All people with cancer are at risk of lymphoedema. The following groups are at higher risk:

- patients with melanoma, lymphoma and sarcomas where lymph nodes have been removed (inguinal) or radical radiotherapy
- it may be a factor in lung cancer at the end of life
- patients with potential lymphoedema of the arm, breast, upper trunk following cancer treatment
- patients with potential lymphoedema following urological cancers requiring surgical intervention, removal of lymph nodes, radical prostatectomy or radical penectomy
- patients with potential lymphoedema following gynaecological cancers requiring surgical removal of lymph nodes, radical radiotherapy, radical hysterectomy or radical vulvectomy

Signs and symptoms of lymphoedema may pre-date treatment for cancer and may be a sign of malignant activity. They could also represent primary lymphoedema, or relate to other secondary causes e.g. vascular damage.

Factors indicating successful treatment intervention will include:

- reduction in limb volume
- reduction in limb circumference

Factors indicating successful treatment intervention will include:

- improvement in skin texture and condition
- psychological improvement
- reduced episodes of cellulitis
- improved dexterity
- reduction in pain

Changes are usually evident in the first 2 weeks of treatment, however for the more chronic presentations this may take up to 6 weeks.

At risk patients should be:

- screened for lymphoedema using bioimpedence, perometry and/or circumferential limb volume measurement*
- encouraged to report any symptoms of lymphoedema and seek referral to a local clinic. Specific risk reducing information should be provided verbally and in written formats (including knowledge of local lymphoedema service).

Education and screening could be provided by a skilled healthcare technician (AfC band 3-4).

Surgical consent, as provided by the medical lead, should include lymphoedema as a potential risk factor for at risk patients. Facilitating early access to lymphoedema services, via patient empowerment and screening, aims to reduce the incidence of chronic presentations, thus improving the treatment outcome and ensuring best use of resources.

*It is important that the same measure is used consistently throughout the interventions.
Rehabilitation Care Pathway Lymphoedema

Diagnosis & Care Planning

Intervention

D1
• Carry out pre-op screening & assessment including limb circumference & medical history

D2
• Provide pre-op information, obtain consent, advise patient of risk of lymphoedema & strategies which will help to reduce risk. Early access to treatment can help to prevent the complex condition developing

Treatment

Intervention

T1
• Provide information prescription and identify keyworker

T2
• Teach self-management and care of affected (or potentially affected) limb/quadrant

T3
• Repeat screening technique & give preventative advice & symptom warning with contact details. (This may become the role of HCA’s in the future)

T4
• Reiterate preventative advice 6-8 weeks post op (oncology/surgical teams)

T5
• Provide reconstructive advice - patients undergoing reconstruction also need preventative advice and may be at risk of developing lymphoedema in back/abdomen due to surgery

T6
• Chemotherapy - provide advice on prevention to protect against damage to at risk limb & warn of potential of oedema as direct side effect of treatment
Rehabilitation Care Pathway Lymphoedema

T7
• **Radiotherapy** – before radiotherapy commences, warn patient of oedema as a direct side effect of treatment. Refer to lymphoedema specialist if this happens for early treatment.

T8
• At risk treatment areas - If patient has had radiotherapy to the following areas, their risk of lymphoedema is higher:
  - Upper limb – head and/or neck region, supraclavicular fossa or axillary area
  - Lower limb - pelvic area
Therefore, provide regular limb volume screening for early detection of symptoms (gold standard) and encourage patient to self-report symptom.

T9
• Advise on recommended exercises, positioning and skincare measures

Post Treatment

Intervention for patients **without lymphoedema** but considered to be at risk i.e. following breast cancer, sarcoma, lymphoma, melanoma. People with gynaecological and urological cancers who have had surgery or radiotherapy to the lymphatic areas. People with metastatic disease

PT1
• Provide preventative advice and contact details of local lymphoedema clinic - give local and national support groups and local clinic contact details. Agree re-access route back into treatment.

PT2
• Some people may be appropriate for prophylactic compression garments despite no swelling but these **must** be fitted & patient assessed by specialists – NB. the risk of fitting a sleeve with no follow up could be detrimental to patient so the decision must be down to the clinical reasoning of the specialist, the patient making an informed choice and if funding is available.
Rehabilitation Care Pathway Lymphoedema

for both the garments and the staff to do an appropriate assessment to fit the correct sleeve or stocking

PT3
• Advice re Body Mass Index & provide dietetic advice if required

PT4
• Help patient return to normal use & active lifestyle.

PT5
• Provide advice & support about issues related to body image & sexual function. Refer on as necessary

PT6
• Manage scar tissue and mobilisation post op

PT7
• Patients without lymphoedema but considered “at risk” should continue to be monitored at the appropriate oncology/surgical team review, encouraged to continue with self care/monitoring and be able to access to up to date information regarding local lymphoedema services for potential future use. This period of surgical monitoring will depend on local practice, therefore patient empowerment is paramount.

Interventions for patients with lymphoedema

PT8
• If additional tests/information are required these can be requested from the referrer GP/Medical Consultant (i.e. cancer treatment history, scans, medications, cancer status etc) People can first develop lymphoedema several years after their original cancer treatment

PT9
• Lymphoedema Specialist will undertake physical, social, psychological, workplace/employment assessments. They will also assess swelling, skin condition, pain, and nutrition as part of holistic care package

PT10
• All patients with lymphoedema should receive a coordinated package of care & information appropriate to their needs. They should provide a
Rehabilitation Care Pathway Lymphoedema

treatment plan agreed with patient and this may involve education and involvement of Carers. Initial management may involve psychosocial support, education, skin care (including education about cellulitis and its management), exercise/movement, elevation and management of secondary complications, pain or discomfort.

PT11
• The patient’s initial management may also include compression hosiery, simple lymphatic drainage and multilayered lymphoedema bandaging (MLLB) and/or Manual Lymphatic Drainage (MLD)

PT12
• Ongoing intensive therapy for complex patients may involve skin care, exercise/movement, elevation, Manual Lymphatic Drainage (MLD), MLLB, Intensive therapy will be provided by a practitioner trained at specialist level.

PT13
• If the patient has any midline lymphoedema, this will need managing by a Lymphoedema Specialist and is likely to include daily skin care, exercise, MLD and/or

simple lymphatic drainage (SLD) (depending on complexity), compression bandaging, compression garments, individualised foam pads & self monitoring

PT14
• Undertake podiatry assessment for patients with lower limb lymphoedema who cannot carry out their own foot care or are at increased risk such as diabetes

PT15
• Refer to MDT members as appropriate for additional supportive care needs

PT16
• Telephone follow up may be suitable for stable patients i.e post CDT (Complex Decongestive Therapy) or to check fit of compression garment

PT17
• Patients who are not responding to lymphoedema management, as per the therapist’s clinical reasoning and judgement, should be referred to a lymphoedema specialist clinic for advice. This should include specialist assessment by vascular, dermatology, oncology &
Rehabilitation Care Pathway Lymphoedema

- Promote access to any local support groups

PT18
- If patient has lymphoedema affecting trunk or genital/supra pubic areas, this will need to be managed by a Lymphoedema Specialist and is likely to include daily skin care, exercise, movement, MLD, and/or simple lymphatic drainage (SLD) depending on complexity, compression bandaging, compression garments, individualised foam pads and self monitoring

PT19
- If genital oedema is present, reiterate skin care, hygiene measures & prompt reporting of cellulitis

PT20
- If patient has lymph cysts with accompanying lymphorrhea referral to a highly specialist lymphoedema practitioner may be required. Patient to report any difficulty with micturition as they may need urological involvement

PT21
- Patients with lymphoedema: provide treatment plan, CDT, regular follow up, cycle of treatment & life long maintenance. Patients may require CDT repeatedly if they experience secondary complications such as recurrent cellulitis

M2
- Patients without lymphoedema but considered “at risk” continue to monitor, ensure self care and provide information about how to access local services potentially in the future & reiterate cellulitis advice
Rehabilitation Care Pathway Lymphoedema

M3
• Ensure patient is aware of any local/national support groups

M4
• Discharge for stable patients to care of GP but with self re-referral back if secondary complication or if significant change in swelling volume

M5
• Assess psychological impact of lymphoedema & refer as appropriate

M6
• Monitor for psychological distress related to body image & sexual issues, pain, weight/BMI & request referral as appropriate

Palliative Care

Intervention

P1
• Introduce adapted treatment plan (CDT etc) and establish realistic goals. Cellulitis is a risk factor at this stage

P2
• Monitor for lymphorrhea & treat urgently

P3
• Patients with existing lymphoedema: adapted treatment plan/CDT

P4
• Refer to additional members of MDT as appropriate

P5
• Aim to prevent risk & secondary complications: cellulitis, lymphorrhea, swelling extending to adjacent area of body, heavy arm which may affect balance
Rehabilitation Care Pathway Lymphoedema

P6
- Patients with fungating wounds & oedematous arm/trunk should be referred to lymphoedema specialist and/or Tissue Viability Nurse Specialist

P7
- Prompt recognition of DVT and investigation

End of Life Care

At risk groups include all advanced cancers. Patients may present with a new diagnosis of lymphoedema at this stage due to tumour obstruction, hypoproteinaemia, immobility, lymphorrhoea

E1
- Ensure thorough investigation to identify cause and make aware they may need medical management prior to, or concurrent with, their lymphoedema management.

E2
- Assessment techniques may need to be modified and individual treatments selected to ease specific symptoms & suited to patient & carer

E3
- Palliative and non invasive management individually suited to each patient and their needs

Interventions for the lymphoedema care pathway will be undertaken mainly by Lymphoedema Specialists/Practitioners who will be mostly physiotherapists, occupational therapists, radiographers, manual lymphatic drainage therapists and nurses skilled & trained at the appropriate level.
National Cancer Action Team