



# Rehabilitation Care Pathway

## Lymphoedema

## 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

\*It is important that the same measure is used consistently throughout the interventions.

- 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.

# Diagnosis & Care Planning

## Intervention

### D1

- Carry out pre-op screening & assessment including limb circumference & medical history
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### 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
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## Treatment

## Intervention

### T1

- Provide information prescription and identify keyworker
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### T2

- Teach self-management and care of affected (or potentially affected) limb/quadrant
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### T3

- Repeat screening technique & give preventative advice & symptom warning with contact details. (This may become the role of HCA's in the future)
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### T4

- Reiterate preventative advice 6-8 weeks post op (oncology/surgical teams)
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### 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
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### 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
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## 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
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## 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, supra clavicular fossa or axillary area
    - Lower limb - pelvic area
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Therefore, provide regular limb volume screening for early detection of symptoms (gold standard)/ and encourage patient to self report symptom

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## T9

- Advise on recommended exercises, positioning and skincare measures
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## 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
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### 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

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

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### PT3

- Advice re Body Mass Index & provide dietetic advice if required
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### PT4

- Help patient return to normal use & active lifestyle.
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### PT5

- Provide advice & support about issues related to body image & sexual function. Refer on as necessary
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### PT6

- Manage scar tissue and mobilisation post op
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### 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.

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## 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
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### 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
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### PT10

- All patients with lymphoedema should receive a coordinated package of care & information appropriate to their needs. They should provide a

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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.

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### 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)
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### 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.
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### 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

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### 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
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### PT15

- Refer to MDT members as appropriate for additional supportive care needs
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### PT16

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

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palliative care medical staff for further assessment and investigations regarding the more complex presentation.

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### 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
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### PT19

- If genital oedema is present, reiterate skin care, hygiene measures & prompt reporting of cellulitis
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### PT20

- If patient has lymph cysts with accompanying lymphorrhoea referral to a highly specialist lymphoedema practitioner may be required. Patient to report any difficulty with micturition as they may need urological involvement
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### PT21

- Promote access to any local support groups
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### PT22

- Research is currently evaluating the role of laser therapy for fibrosis management and IPC as an adjunct to CDT. There is no national agreement to date on the use of these modalities, and further research is recommended.
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## Monitoring/ Survivorship

### M1

- 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
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### 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
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### M3

- Ensure patient is aware of any local/national support groups
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### 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
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### M5

- Assess psychological impact of lymphoedema & refer as appropriate
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### M6

- Monitor for psychological distress related to body image & sexual issues, pain, weight/BMI & request referral as appropriate
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## Palliative Care

### Intervention

#### P1

- Introduce adapted treatment plan (CDT etc) and establish realistic goals. Cellulitis is a risk factor at this stage
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#### P2

- Monitor for lymphorrhoea & treat urgently
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#### P3

- Patients with existing lymphoedema: adapted treatment plan/CDT
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#### P4

- Refer to additional members of MDT as appropriate
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#### P5

- Aim to prevent risk & secondary complications: cellulitis, lymphorrhoea, swelling extending to adjacent area of body, heavy arm which may affect balance
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### P6

- Patients with fungating wounds & oedematous arm/trunk should be referred to lymphoedema specialist and/or Tissue Viability Nurse Specialist
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### P7

- Prompt recognition of DVT and investigation
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## 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.
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### E2

- Assessment techniques may need to be modified and individual treatments selected to ease specific symptoms & suited to patient & carer
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### E3

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

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