CANCER REHABILITATION PATHWAYS

Zoe and her mother's Macmillan nurse Margaret

MACMILLAN CANCER SUPPORT

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Introduction

In 2013 The National Cancer Action Team worked to establish the evidence base for cancer rehabilitation and the subsequent interventions which take place at each stage. This pathway is the culmination of that work. Though a legacy document, it is still useful and an important contribution to describing and illustrating the role of Allied Health Professionals (AHPs) in cancer rehabilitation for people living with and beyond cancer. It supports the recommendations laid down by the Cancer Taskforce (Achieving World Class Cancer Outcomes: A strategy for England 2015–2020).

The pathways, which are aimed at those working with adults affected by cancer, have been designed for use by AHPs and other healthcare professionals in cancer and palliative care, as well as provider and commissioning organisations. The pathways are provided as a guide to the types of rehabilitation interventions which patients may need at different stages of their treatment. The cancer rehabilitation pathways were produced using evidence from two reviews undertaken by the National Cancer Rehabilitation Advisory Board: Cancer and Palliative Care Rehabilitation: A Review of the Evidence (2009); and Cancer and Palliative Care Rehabilitation: A Review of the Evidence Update (January 2012).

Current version of the cancer rehabilitation pathways

Following feedback from AHPs across the UK there were many requests that the cancer rehabilitation pathways be available and accessible to all working with those affected by cancer. We have listened to this feedback and bring you the output of phase 1 of a two-phase project. In this phase this version of the cancer rehabilitation pathways has been refreshed (from the original NCAT work described above) with the prime aim of ensuring the pathways are accessible and navigable to healthcare professionals.

We would very much welcome your comments on this current version of the pathways via an online survey link which can be found next to the interactive PDF on the Macmillan website. We will use the feedback you provide via the online survey to inform phase 2 of the work.

Phase 2 of the work will start in July 2018 and will aim to ensure that the pathways are contemporary, link to current national policy and have further content added based on emerging evidence that has developed over the last few years.

Please use the following Twitter hashtag: #CancerRehab if you would like to tweet about the pathways.

Allied Health Professionals' roles

Cancer rehabilitation involves a wide range of AHPs carrying out distinct roles throughout the pathway. The main roles covered in the pathways are: dietitians, lymphoedema practitioners, occupational therapists, physiotherapists and speech and language therapists. They deliver specialist interventions that complement the skills of other multidisciplinary team members. Different patients will have different rehabilitation needs, depending on the type, location and stage of their cancer. It is acknowledged that healthcare professionals, including both registered and unregistered staff including support workers, may also contribute to the rehabilitation of people affected by cancer.

About rehabilitation

Rehabilitation is a central element of cancer care and a key theme of the Cancer Taskforce recommendations. It enables patients to make the most of their lives by maximising the outcomes of their treatment and minimising the consequences of treatment and symptoms such as fatigue, breathlessness and lymphoedema. The need for rehabilitation starts at the point of diagnosis by helping patients prepare for treatment ('prehabilitation') and discharge home. It can help patients get well and stay well and addresses the practical problems caused by the disease and treatment, helps patients become as independent as possible and minimise the impact on carers and support services.

Acknowledgements

Macmillan Cancer Support would like to fully acknowledge the National Cancer Action Team for the original development of this work and to thank Health Education England, NHS England Cancer Transformation Programme, the Transforming Cancer Services Team (part of the Healthy London Partnership) and members of the Macmillan AHP expert advisory group for all their advice and contributions to the development of this document.

The pathway
There are three main components of the pathway:

1) **Generic interventions** – includes interventions which may be relevant to ANY type of primary cancer, ie provide advice about general exercise programme, provide nutritional assessment. (NB. A patient with cancer is unlikely to need every intervention). The pathway covers four key stages:
   - Diagnosis and care planning
   - Treatment
   - Post-treatment
   - Palliative and end of life care

2) **Specific interventions** – these include interventions which are specific to a small number of cancer sites, ie managing communication, voice and swallowing problems following treatment for brain, breast, lung, head and neck, sarcoma, gynaecology, upper gastrointestinal, lower gastrointestinal, haematology, colorectal, skin and urology

3) **Symptom pathways** – there are symptoms that patients experience which can occur at different stages in the pathway. Interventions to support those with any of the symptoms below are included in the PDF including:
   - Anorexia/Cachexia/Weight loss
   - Breathlessness
   - Communication
   - Continence
   - Dysphagia
   - Fatigue
   - Lymphoedema
   - Metastatic spinal cord compression
   - Mobility
   - Pain

DIAGNOSIS AND CARE PLANNING

Patrick, living with cancer


Diagnosis and care planning
Treatment
Post-treatment
Palliative and end of life care
Symptoms

Assessment

Generic

- Undertake baseline holistic care assessment considering:

  General assessment:

  – independent functional status
  – quality of life and daily living
  – fatigue
  – anxiety and depression
  – mood and coping strategies
  – smoking and alcohol use
  – lifestyle.

- Undertake a pre-operative/pre-treatment risk assessment where appropriate considering:

  1) Current extent of disease.
  2) Development of post-operative problems such as high levels of anxiety, history of chronic pain, existing musculoskeletal conditions.
  3) Impact of comorbidity on treatment interventions.
  4) Identify and educate patients about pre-op risk factors

(Note many patients do not undergo surgery but do have radiotherapy or hormone treatment.)

- Assess and manage cancer treatment effects where any functional or co-morbidities affecting functional independence are identified.

Specific >

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Diagnosis and care planning

Assessment (continued)

Specific

- Undertake specialist disease and symptom related assessments:
  1) Undertake cognitive assessment.
  2) Assess patient's circumstances and ability to act on advice.
  3) Carry out full assessment of functional ability, cognitive and perceptual ability and social situation.
  4) Assess communication and impact treatment or cognitive changes may have on this.
  5) Assess swallowing and impact treatment may have.
  6) Undertake functional and neurological assessment to improve quality of life including mobility, exercise tolerance, functional task, balance, vestibular and upper limb function.
  7) Undertake assessment that monitors and records weight, height and waist as a bench mark to enable any weight gain or loss to be monitored.
  8) Assess respiratory function, mobility, muscle strength, symptom/side effects.
  9) Allocation of appropriate outcome measures.
- For cancers involving, or in the location of lymph nodes, undertake limb volume measurements (see Lymphoedema).
- Assess patients to include the possibility of pathological fracture and spinal cord compression especially in cancers of the breast, lung, skin, prostrate, renal, ovarian, teenage and young adult sarcoma and myeloma.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Activities of daily living

Generic

Assessment

- Daily living activities including:
  1) Undertake assessment of domestic care ability.
  2) Undertake an environmental assessment (with or without patient present) and adaptations/ equipment where this is appropriate.
  3) Assess for and access compensatory strategies, adaptive techniques and equipment.
- Assess levels of fatigue and advise as necessary.

Specific to gynaecology, colorectal, urology

Assessment

- Assess and assist in management of incontinence.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Cognitive and psychological factors

Generic

Assessment

- Assess, plan and engage in anxiety management programme in order to provide confidence for patient and/or carers in management of condition. Suggest coping strategies. Use cognitive behavioural therapy techniques where appropriate. Refer on to appropriate specialist if necessary.

Treatment or referral

- Identify psychological needs and offer up to level 2 psychological support throughout assessment and treatment and refer as necessary to psychological services and other support groups.
- Retrain in order to help patient with cognitive and perceptual dysfunction.
- Teach relaxation and structured sleep techniques.
- Suggest restorative or compensatory therapy interventions.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Communication

Specific to head and neck, haematology, upper gastrointestinal screening

Screening

- Screen for communication difficulties including vocal cord palsy. This is an indication of recurrent laryngeal palsy.

Specific to lung, head and neck

Assessment

Provide pre-treatment AHP assessment to:

1) Assess baseline communication.
2) Assess impact of cognitive changes on communication.
3) Advise surgeon of potential methods of communication including surgical voice restoration and patients ability to manage the options.
4) Advise patient regarding potential communication aids.
5) Prepare patient and carers for potential changes and advise on communication strategies using treatment.
6) Provide prophylactic exercises to maintain communication and prevent complications from treatment.

Specific to lung

Treatment or referral

- Patients with troublesome hoarseness should be referred to an ear, nose and throat specialist for advice.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Exercise

Generic

Treatment or referral
Provide advice about exercise including:

1) General exercise programme to increase or maintain independence.
2) Maintain restorative exercise and health promotion as possible preoperatively.
3) Specific disease exercises, eg shoulder specific, respiratory fitness.
4) Intervene to help patient improve and maintain stamina, function and activity tolerance through exercise prescription.
5) Teach exercises for areas to be treated by radiotherapy to ensure reduction in pain, recovery of movement and improve function.

Consider use of prehabilitation programme prior to planned surgery to include any or all of the following:

1) Full assessment.
2) Exercise programme.
3) Education and self-management.
4) Advice on lifestyle choices.
5) Information on disease and treatment process.
6) Pain management techniques.

Information/support

Generic

Treatment or referral

- Assess information needs for patients and provide suitable verbal and written advice, using information prescriptions if available.
- Provide and facilitate carer support, advice and information including referral to support groups using available media.
- Provide information on maintenance techniques to take forward including information on posture, wound infection, lymphoedema, cording (axillary web syndrome), postop scar management sensation changes, post-op timeline and complications and any other risk factors.
- Provide information and ensure patient choice in decision of treatment (advocate). Support/assist patient consent process.
- Ensure information for teenage and young adult patients is appropriate to their age.

Education
Educate patient on:

1) role of rehabilitation staff
2) referral procedure
3) contact details
4) awareness of symptoms and at what point patient needs to take action

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Mobility and wellbeing

Generic

Assessment

- Where necessary, assess, advise and implement positioning and seating and postural advice in liaison with MDT as needs/symptoms require.
- Undertake risk assessment for falls and manual handling and provide safety advice.
- Carry out mobility assessment including:
  1) mobility
  2) transfers
  3) personal assessment
  4) domestic activities of daily living
  5) environmental adaption needs
  6) provision of equipment including wheelchair
  7) assessment of postural management and seating

Specific to haematology, colorect, skin, sarcoma

Treatment or referral

- Assess and advise on hand dexterity, eye sight and cognitive abilities where difficulties may be anticipated (eg managing stoma, prosthesis, etc).

Specific to lung, upper gastrointestinal

Treatment or referral

- Suggest non pharmacological intervention for pain management and nausea and vomiting.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Nutrition

Generic

Assessment

Nutritional assessment of the patient (where appropriate) to include:

1) Review of current nutritional intake
2) Current nutritional problems as a result of disease, symptoms or cancer treatment
3) Degree of nutritional depletion and the likelihood of further nutritional depletion
4) Nutritional implications of specific tumour types
5) Physical state
6) Current food and drink intake
7) Anthroprometric measurements
8) Biochemistry
9) Nutritional requirements (energy, protein, fluid, electrolytes, micronutrients, fibre) using validated assessment tools and methods

Screening

- Implement nutritional screening – Screen all patients nutritionally at each outpatient, admission to hospital and/or in the community/primary care.

Treatment or referral

- Devise an individualised nutritional care plan providing practical dietary advice tailored to the individuals needs, prognosis, symptoms, and circumstances and ensure interventions are commenced. Refer to other team members as appropriate.
- Provide counselling on eating and drinking problems and perioperative feeding. Provide on-going dietetic monitoring and support to patient, family and carers/ relatives.
- Where appropriate to the patients needs/diagnosis/ other conditions they may present with, provide relevant therapeutic dietary advice eg diabetes, coeliac renal dysfunction (low potassium, low phosphate, sodium and fluid restrictions) as appropriate.

Education

- Influence organisational approach to provision of food and drink.

Specific >

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Specific

Treatment or referral

Where appropriate commence pre-surgical/ perioperative, and continue through treatment, oral/ enteral/parenteral nutritional support to help improve quality of life:

1) Provide advice on weaning from enteral tube feeding to oral diet
2) Provide education regarding feeding tube management and the administration of feed
3) Plan and coordinate enteral feeding tube discharges and ensure referral to community services for continued support
4) Liaise with home enteral feeding team for changes to feeding regime
5) For patients requiring home total parenteral nutrition follow local guidelines

Specific to upper gastrointestinal

Treatment or referral

- Consider use of immunonutrition for immuno suppressed patients.
- Advise on use of pancreatic enzymes replacement therapy (PERT) including advice regarding proton pump inhibitor (PPI).
- Advise on fat soluble vitamin supplementation for patients on/requiring PERT.

Specific to colorectal

Treatment or referral

- Consideration needs to be given to a multidimensional approach to dietary advice and treatment including food and drink intake and dietary supplements.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Referral/liaison

Generic

Treatment or referral

- Attend MDT meetings to obtain referrals, update team on patients progress and handover care.
- Establish and advise medical staff on proposed treatment plan.
- Refer to other health care professional, team members, including extended team members, if appropriate and ensure access to ongoing support specifically required by patient.
- AHPs to liaise with keyworker and keyworker contact details provided. (AHPs may also be the keyworker.)
- If early transfer of care is appropriate arrange outpatient or community rehabilitation services or palliative care and provide appropriate contact numbers to patients and family. Refer to support groups, self help group, expert patient programmes, Living With Cancer course.
- Facilitate timely and appropriate referral to domiciliary physiotherapy social services, other supportive care services etc.

Specific to sarcoma

Treatment or referral

- Ensure patient referred to a specialist sarcoma occupational therapist/physiotherapist (level 4) at specialist sarcoma centre.

Specific to head and neck

Treatment or referral

- Advise on AHP clinic availability for patients requiring rapid access to supportive care.
- Refer using generic AHP/oncology assessment tool during assessment by medical/nursing/AHP staff doing the screening.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Respiratory function

Generic

Assessment

- Identify patient with pre-existing respiratory disease, if patient is to be referred for surgery or it may impact on the recovery process.

Treatment or referral

- Commence chest physiotherapy to suit individual requirements and optimise physical respiratory fitness prior to surgery.

Skin and soft tissue management

Generic

Assessment

- Undertake assessment and nonpharmacological management of altered skin sensation. Especially relevant to colorectal, haematology (particularly with thalidomide treatment which is associated with severe neuropathy) and gynaecological cancers.
- Assess skin integrity in pressure areas and refer for pressure relieving equipment if necessary.

Treatment or referral

- Assess for and arrange provision of pressure relieving cushions mattresses to optimise comfort and minimise the risk of developing or exacerbating existing pressure sores.

Specific

Treatment or referral

- Initiate complex seating and pressure management aiming to improve sitting tolerance in the initial stages.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Swallowing

Specific

Assessment

- Assess oropharyngeal swallow function where indicated.

Treatment or referral

- Provide information pre-operatively for patients who are high risk for pharyngeal phase dysphagia postoperatively, such as those undergoing an oesophagectomy with neck anastomosis.

Work and lifestyle

Generic

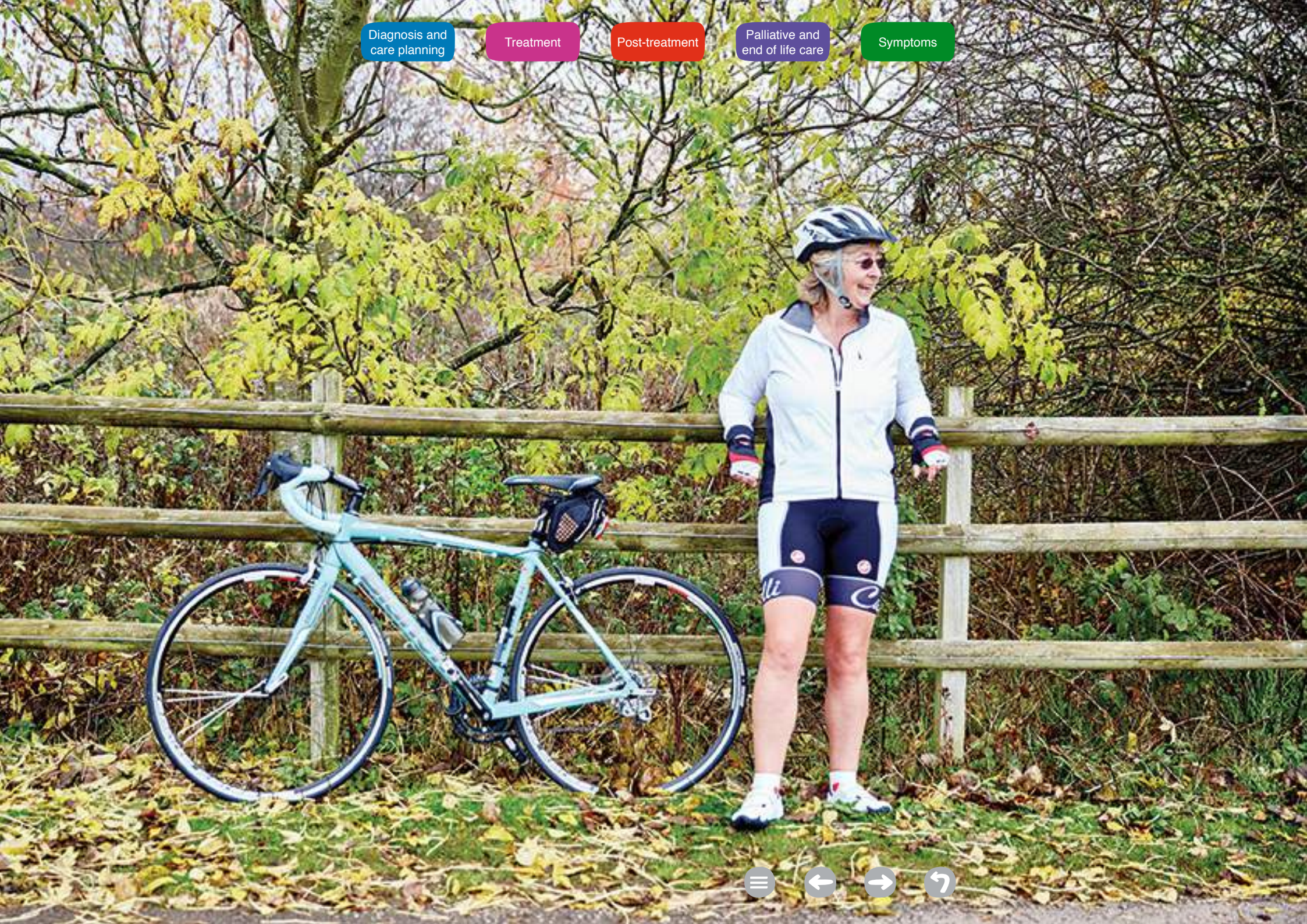
Assessment

- Address issues regarding patients work/education including:
  1) Identify patient needs and goals around occupation
  2) Provide vocational rehabilitation and advice on return to work/education/voluntary work as appropriate
  3) Address any specific issues for teenage and young adult patients
- Lifestyle management considering:
  1) Obtain information on social situation and support network
  2) Screen for sexual functioning and refer on as necessary
  3) Manage lifestyle adjustment including roles
- Assess patients social needs as a client-led priority for teenage and young adult patients, ie engaging in hobbies, interests, learning to drive, etc.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Jane, living with cancer

TREATMENT


Diagnosis and care planning
Treatment
Post-treatment
Palliative and end of life care
Symptoms

Assessment

Generic

- Undertake baseline holistic care assessment considering:

  General assessment:

  – independent functional status
  – quality of life and daily living
  – fatigue, anxiety and depression
  – mood and coping strategies
  – smoking and alcohol use
  – lifestyle.

- Undertake pre-surgical assessment in clinic, as appropriate, and identify any pre-existing problems that may be exacerbated by surgery.
- Assess and manage cancer treatment effects where any functional or co-morbidities affecting functional independence are identified.
- Assess pre-existing functional status to establish a base line measurement. Pre-empt the impact of treatment modalities and/or surgery/post operative precautions on functional status and plan treatment sessions/referrals accordingly.
- Undertake comprehensive post-op assessments for any impairments, loss of function, joint range, muscle strength, abnormal muscle tone neurological deficits.
- Undertake baseline assessment of physical fitness and review subsequently as required.
- Assess psychological needs of patients, families and carers and refer on or provide advise appropriately.

Specific >

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Treatment

Assessment (continued)

Specific

- Undertake SPECIALIST disease related assessments:
  1) Undertake cognitive assessment.
  2) Assess patient's circumstances and ability to act on advice.
  3) Carry out full assessment of functional ability, cognitive and perceptual ability and social situation.
  4) Assess communication and impact treatment or cognitive changes may have on this.
  5) Assess swallowing and impact treatment may have.
  6) Perform instrumental assessments of the vocal tract including vocal fold function and voice when clinically appropriate.
  7) Perform instrumental assessments of dysphagia including videofluoroscopy (vf) when clinically appropriate and/or fibre optic endoscopic examination (FEES) when clinically appropriate.
  8) Undertake functional and neurological assessment to improve quality of life including mobility, exercise tolerance, functional task, balance, vestibular and upper limb function, range of movement, muscle tone, musculo-skeletal and skin condition.
  9) Undertake assessment that monitors and records weight, height and waist as a bench mark to enable any weight gain or loss to be monitored.
  10) Assess respiratory function, mobility, muscle strength, symptom/side effects.
  11) Undertake airway assessment.
  12) Undertake assessment which includes Psychological status and mood.
- Measure and record pre and post op limb circumference (or limb volume) measurement if patient is undergoing surgery or radiotherapy involving, or in the location of, lymph nodes.
- Assess patients to include the possibility of pathological fracture and spinal cord compression especially in cancers of the breast, lung, skin, prostrate, renal, ovarian, teenage and young adult sarcoma and myeloma.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Specific to haematology intervention

- Monitor degree of immune suppression.
- For teenage and young adult patients: assess patients for avascular necrosis. Assessment of pain in the joints (particularly weight bearing joints), altered range of movement, change in function due to joint problems. If suspected, liaise with treating team and ensure physiotherapist and occupational therapist referrals.

Specific to head and neck

- Re assess swallow function and instigate dysphagia therapy.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Treatment

Activities of daily living

Generic

Assessment

- Daily living activities including:
  1) Undertake assessment of domestic care ability.
  2) Undertake an environmental assessment (with or without patient present) and adaptations/ equipment where this is appropriate.
  3) Assess for and access compensatory strategies, adaptive techniques and equipment.
  4) Respond to variations in functional ability providing rehabilitation classes if required.
- Assess levels of fatigue and advise as necessary.

Treatment or referral

- Ensure aids and equipment to facilitate independence and/or care in activities of daily living are delivered and fitted prior to discharge according to local guidance including. Amputee Mobility Aid (AMA) or PPAM Aid (Pneumatic Post Amputation Mobility Aid) for amputee patients.
- Address issues such as clothing that requires minimum effort to get on and is comfortable particularly with patients with prosthetics/stomas/ lines/drains.
- Advise on compensatory techniques, especially following major head and neck reconstructions.

Education

- Maintain awareness of wider issues of cancer prognosis and the impact of treatment on self image.

Specific to breast, sarcoma

Treatment or referral

- PRE OP and/or POST OP – Re-educate on pain, precautions to take with activities of daily living (no heavy activities), general well being and fitness, sensation changes, scar massage, wound infection and healing, haematoma signs and symptoms, postural awareness, returning to driving, lymphoedema, seroma, cording (axillary web syndrome) signs and symptoms and how to treat this using soft tissue techniques, phantom limb pain, seroma, oedema.

Specific to gynaecology, colorectal, urology

- Assess and assist in management of incontinence.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Cognitive and psychological factors

Generic

Treatment or referral

- Assess, plan and engage in anxiety management programme in order to provide confidence for patient and/or carers in management of condition. Suggest coping strategies. Use cognitive behavioural therapy techniques where appropriate. Refer on to appropriate specialist if necessary.
- Identify psychological needs and offer up to level 2 psychological support throughout assessment and treatment and refer as necessary to psychological services and other support groups.
- Retrain in order to help patient with cognitive and perceptual dysfunction.
- Teach relaxation and structured sleep techniques/ management.
- Manage mood through compensatory strategies
- Discuss and help patients to explore their feelings around body image, self esteem, self-identity, confidence, sexuality and relationships.
- Assess and advise strategies to manage role adjustment and refer on to other agencies.

Specific to brain, haemotology

- Implement memory strategy – Assess for and arrange provision of memory aids.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Communication

Specific to head and neck

Treatment or referral

- Work with MDT to ascertain the cause of communication or swallowing difficulty.
- Carry out videofluoroscopy X-ray if appropriate for investigation of poor voicing.
- Support, teach and advise relatives of appropriate communication channels.
- Give patient appropriate oro-motor range of motion and strengthening exercises in collaboration with the medical/surgical teams.
- Instigate the whole programme for surgical voice restoration (SVR) and prepare for voice prosthesis fitting including selection of appropriate prosthesis , preparation of patient and attend theatre.
- Fit voice prosthesis and teach patient, family, carers, nursing staff as appropriate about care and maintenance.

Specific to head and neck, lung

Treatment or referral

- Provide equipment and materials and teach their use to patients and carers.
- Provide advice and management for all patients referred with compromised speech, communication, voice and swallowing mechanisms.

Specific to lung

Treatment or referral

- Carry out instrumental assessment of vocal tract function/

Specific to upper gastrointestinal

Treatment or referral

- Inform ear, nose and throat if vocal fold dysfunction or palsy is suspected. If confirmed treat.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Specific to brain, head and neck

Treatment or referral

- Undertake tracheostomy assessment and care.

Specific to brain

Treatment or referral

- Intraoperative language assessment provided by SLT or clinical psychology for patients undergoing an 'Awake' craniotomy where MDT deem it necessary.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Exercise

Generic

Treatment or referral

- Provide disease related exercise including:
  1) Advise on fibrosis pre treatment and treat if appropriate with soft tissue massage.
  2) Assess/manage range of movement – assess any other musculoskeletal problems related to any plastic surgery.
  3) Teach stretching exercises at the start of treatment.
  4) Teach patient exercises for maintenance of circulation and general muscle strength if the patient is acutely unwell.
  5) Teach patient exercises for maintenance of circulation and general muscle strength if the patient is unable to mobilise.
  6) Teach exercises for areas to be treated by radiotherapy to ensure reduction in pain, recovery of movement to improve function.
  7) Provide tailored exercise advise/intervention appropriate to all patients throughout the treatment pathway.
- Teach post operative exercises for neck, arm and shoulder, facial, abdominal, temperomandibular joint and any other area affected by surgery and plastic reconstruction to ensure reduction in pain, reduction of scar formation, recovery of movement and improve function.
- Provide exercise intervention for all patients undergoing high dose chemotherapy.
- Help improve exercise tolerance by providing advice and education on maintaining (or increasing) physical activity levels to improve fitness and wellbeing – possibly through a general exercise programme or exercise classes.

Specific ›

Anorexia/cachexia/ weight loss ›
Breathlessness ›
Communication ›
Continence ›
Dysphagia ›
Fatigue ›
Lymphoedema ›
Metastatic spinal cord compression ›
Mobility ›
Pain ›

Specific to sarcoma

Treatment or referral

- Admits patients for in-patient physiotherapy in hydrotherapy pool and physiotherapy gym after endoprosthetic replacement when required.

Specific to head and neck

Treatment or referral

Provide specific disease related exercise including:

1) Undertake musculo-skeletal assessment of neck and temporomandibular joint disorders and treat as appropriate.
2) Assess and treat facial nerve palsy If required, advise patient about managing continence problems through pelvic floor exercises, with written support materials.

Specific to gynaecology, colorectal, urology

Treatment or referral

- If required, advise patient about managing continence problems through pelvic floor exercises, with written support materials.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Information/support

Generic

Assessment

- Assess information needs for patients and provide suitable verbal and written advice, using information prescriptions if available.

Treatment or referral

- Provide and facilitate carer support, advice and information including referral to support groups using available media.
- Provide information on post op routine and signpost to relevant services including patient support and education groups.
- Support and advise on longer term post-op management including awareness of symptoms associated with cancer and cancer treatments such as:
  1) Educate on soft tissue and bone healing process.
  2) Give advice on the potential for peripheral neuropathy following chemotherapy.

Education

- Ensure information for teenage and young adult patients is appropriate to their age.

Specific to breast haematology sarcoma

Treatment or referral

- If metastatic bone disease, avascular necrosis or osteoporosis have been identified provide precautionary and preventative information about protecting vulnerable bones.

Specific to sarcoma

Treatment or referral

- Educate on specific precautions relating to endoprosthetic replacement (ie No contact sports, running, twisting, hopping or jumping).

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Mobility and wellbeing

Generic

Specific >

Assessment

Carry out mobility assessment including:

1) mobility
2) transfers
3) personal assessment
4) domestic activities of daily living
5) environmental adaption needs
6) provision of equipment including wheelchair
7) assessment of postural management and seating

Treatment or referral

- Provide positioning and seating and postural advice in liaison with MDT as needs/symptoms require.
- Undertake risk assessment for falls and manual handling and provide safety advice.
- Advise patient and carers about effective lifting and general activity, (including use of equipment and techniques) or safe moving and handling. Provide written support materials if required.
- Ensure provision of equipment necessary for rehabilitation including orthotics, prosthetics, wheelchair provision.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Specific to brain

Assessment

- Undertake assessments for vestibular problems, joint range and deformities, seating and positioning.

Treatment or referral

- Provide neurological rehabilitation to help improve normal muscle tone, balance, mobility and functional activities.

Monitoring/review

- Provide ongoing monitoring of function throughout radiotherapy/chemotherapy stages.

Specific to breast, sarcoma

Treatment or referral

- Provide advice on early active movement and tissue massage to reduce scar formation.

Specific to haematology, colorectal, skin, sarcoma

Treatment or referral

- Discuss and provide alternative strategies where hand dexterity, eye sight and cognitive abilities make managing stoma and prosthesis difficult.

Specific to lung, upper gastrointestinal

Treatment or referral

- Suggest non pharmacological intervention for pain management and nausea and vomiting specific to sarcoma.

Specific to sarcoma

Treatment or referral

- Ensure provision of compression hosiery for lymphoedema or residual limb oedema.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Nutrition

Generic

Assessment

Nutritional assessment of the patient (where appropriate) to include:

1) Review of current nutritional intake.
2) Current nutritional problems as a result of disease, symptoms or cancer treatment.
3) Degree of nutritional depletion and the likelihood of further nutritional depletion.
4) Nutritional implications of specific tumour types.
5) Physical state.
6) Current food and drink intake.
7) Anthropometric measurements.
8) Biochemistry.
9) Nutritional requirements (energy, protein, fluid, electrolytes, micronutrients, fibre) using validated assessment tools and methods.

Treatment or referral

- Devise an individualised nutritional care plan providing practical dietary advice tailored to the individuals needs, prognosis, symptoms, and circumstances and ensure interventions are commenced. Refer to other team members as appropriate.
- Where appropriate to the patients needs/diagnosis/other conditions they may present with, provide relevant therapeutic dietary advice eg diabetes, coeliac, renal dysfunction (low potassium, low phosphate, sodium and fluid restrictions) as appropriate.
- Provide on-going advice and manage symptoms post treatment such as reflux, regurgitation, dumping syndrome, early satiety, poor appetite, nausea, vomiting, bloating and bowels, taste changes and mouth care, dysphagia, texture modification, diarrohoea.
- Where appropriate, advise on healthy eating, fatigue, weight maintenance, alternative diets, vitamins, minerals and herbal supplements. Provide practical healthy eating advice in particular to those with a high BMI.
- Provide counselling on eating and drinking problems and perioperative feeding. Provide on-going dietetic monitoring and support to patient, family and carers/relatives.

Anorexia/cachexia/weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Treatment

Nutrition (continued)

Screening

- Implement nutritional screening – Screen all patients nutritionally at each outpatient, admission to hospital and/or in the community/primary care.

Education

- Influence organisational approach to provision of food and drink.
- Educate and apply appropriate food safety restrictions.

Specific ›

Anorexia/cachexia/ weight loss ›
Breathlessness ›
Communication ›
Continence ›
Dysphagia ›
Fatigue ›
Lymphoedema ›
Metastatic spinal cord compression ›
Mobility ›
Pain ›

Specific

Treatment or referral

Where appropriate commence presurgical/ perioperative, and continue through treatment, oral/ enteral/parenteral nutritional support to help improve quality of life:

1) Provide advice on weaning from enteral tube feeding to oral diet.
2) Provide education regarding feeding tube management and the administration of feed.
3) Plan and Coordinate enteral feeding tube discharges and ensure referral to community services for continued support.
4) Liaise with home enteral feeding team for changes to feeding regime.
5) For patients requiring home total parenteral nutrition follow local guidelines.

Specific to upper gastrointestinal, haematology

Treatment or referral

- Monitor and identify biochemistry, full blood count, electrolyte disturbance, renal function , anthropometrics and re-feeding syndrome and advise/refer as appropriate.

Specific to upper gastrointestinal, lung

Treatment or referral

- Advise on oesophageal stenting if applicable.

Specific to upper gastrointestinal

Treatment or referral

- Consider use of immunonutrition for immuno suppressed patients.
- Undertake assessment and advise on use of pancreatic enzymes (PERT) including advice regarding proton pump inhibitor (PPI). Advise on micronutrients (fat soluble vitamins) on PERT.

Specific to colorectal

Treatment or referral

- Consideration needs to be given to a multidimensional approach to dietary advice and treatment including food and drink intake and dietary supplements.
- A combined programme of exercise and dietary advice has a positive effect on exercise behaviour and change in dietary fibre intake.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Referral/liaison

Generic

Treatment or referral

- Advise and liaise with MDT including
  1) Referral to other specialist professions.
  2) Check and analyse medical notes and decide on appropriate individualised treatment plan.
  3) Provide strategic planning and case management.
  4) Identify and contribute to complex discharge needs and instigate discharge planning in liaison with MDT in Assessment Clinic.
- Refer to other health care professional, team members, including extended team members, if appropriate and ensure access to ongoing support specifically required by patient.
- AHPs to liaise with keyworker and keyworker contact details provided. (AHPs may also be the keyworker.)
- As part of the discharge process, arrange outpatient or community rehabilitation services or palliative care and provide appropriate contact numbers to patients and family.
- Refer to support groups, self help group, expert patient programmes, Living With Cancer course.

Specific >

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Specific to brain

Treatment or referral

Refer to community/primary care teams and specialist neuro/cancer teams if available. They should also be referred to these teams throughout the pathway as care will transfer between community and acute settings dependant upon the patient's overall management. They may go home between treatments and there should be a smooth flow between acute/community teams to reflect this.

Specific to colorectal

Treatment or referral

- Liaise with colorectal team preoperatively regarding stoma site where there are concerns surrounding post-op functioning due to other disability.

Specific to haematology

Treatment or referral

- For teenage and young adult patients: if avascular necrosis is suspected ensure referral for orthopaedic opinion.

Specific to head and neck

Treatment or referral

- Screen for facial problems, eg facial palsy, need for prosthetics, etc, and refer to other professionals for assessment and management.

Specific to sarcoma

Treatment or referral

- For patients with amputation and/or extensive surgery, liaise with local occupational therapist and physiotherapy teams for appropriate input eg access visit.
- For patients requiring amputation, refer to the local prosthetic rehabilitation unit for pre-operative assessment.

Anorexia/cachexia/weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Respiratory function

Generic

Treatment or referral

- Identify patient with pre-existing respiratory disease, if patient is to be referred for surgery or it may impact on the recovery process.
- Commence and provide ongoing chest physiotherapy to suit individual requirements to achieve optimal respiratory status and aid clearance of secretions.
- Teach patient methods for secretion clearance, supported cough and provide ongoing chest physiotherapy.
- Teach patient methods for secretion clearance, supported cough and provide ongoing chest physiotherapy.
- Provide pulmonary rehab pre and post surgery, chemotherapy and radiotherapy.

Specific to head and neck

Treatment or referral

- Advise on selection, care and use of:
  1) laryngectomy tracheostoma valves.
  2) advise and fit hands free tracheostoma valve.
  3) laryngectomy stoma filters (heat moisture exchange filters).
- Assist patient to manage respiratory function including tracheostomy care and weaning.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Skin and soft tissue management

Generic

Treatment or referral

- Assess for and arrange provision of pressure relieving cushions/mattresses to optimise comfort and minimise the risk of developing or exacerbating existing pressure sores.
- Mouth care – Establish treatment plans, assess condition of mouth including mucosa and pain and encourage oral hygiene and use of mouth washes.
- Assess, educate and advise on daily skin care.
- Assess skin integrity in pressure areas and refer for pressure relieving equipment if necessary.

Specific to breast

Treatment or referral

- Assess potential for cording and massage scar as appropriate. Be aware of skin care.

Specific to haematology sarcoma

Treatment or referral

- Provide advice on the potential for/or splinting for peripheral neuropathies.
- Assess and monitor for signs of graft versus host disease (GVHD).
- Liaise with medical team for analgesia as required.

Specific to skin sarcoma

Treatment or referral

- Advise on fibrosis pre treatment and treat if appropriate.
- Manage skin grafts and flaps as per guidance from surgeons in conjunction with expertise in tissue repair and educate patient on precautions relating to plastic surgery.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Swallowing

Specific to brain

Assessment

- Undertake tracheostomy assessment and care.

Specific to upper gastrointestinal

Assessment

- Assess orophanyngeal swallow function and monitor regularly for change.
- Carry out instrumental assessment of swallowing function.

Treatment or referral

- Joint contrast swallow/videofluoroscopy with.
- Radiology may be of benefit if there are aspiration issues in high risk patient with neck anastomosis.
- Refer to local Speech and Language Therapy for follow up +/- videofluoroscopy, as appropriate.
- Treat for identified swallowing difficulties.

Work and lifestyle

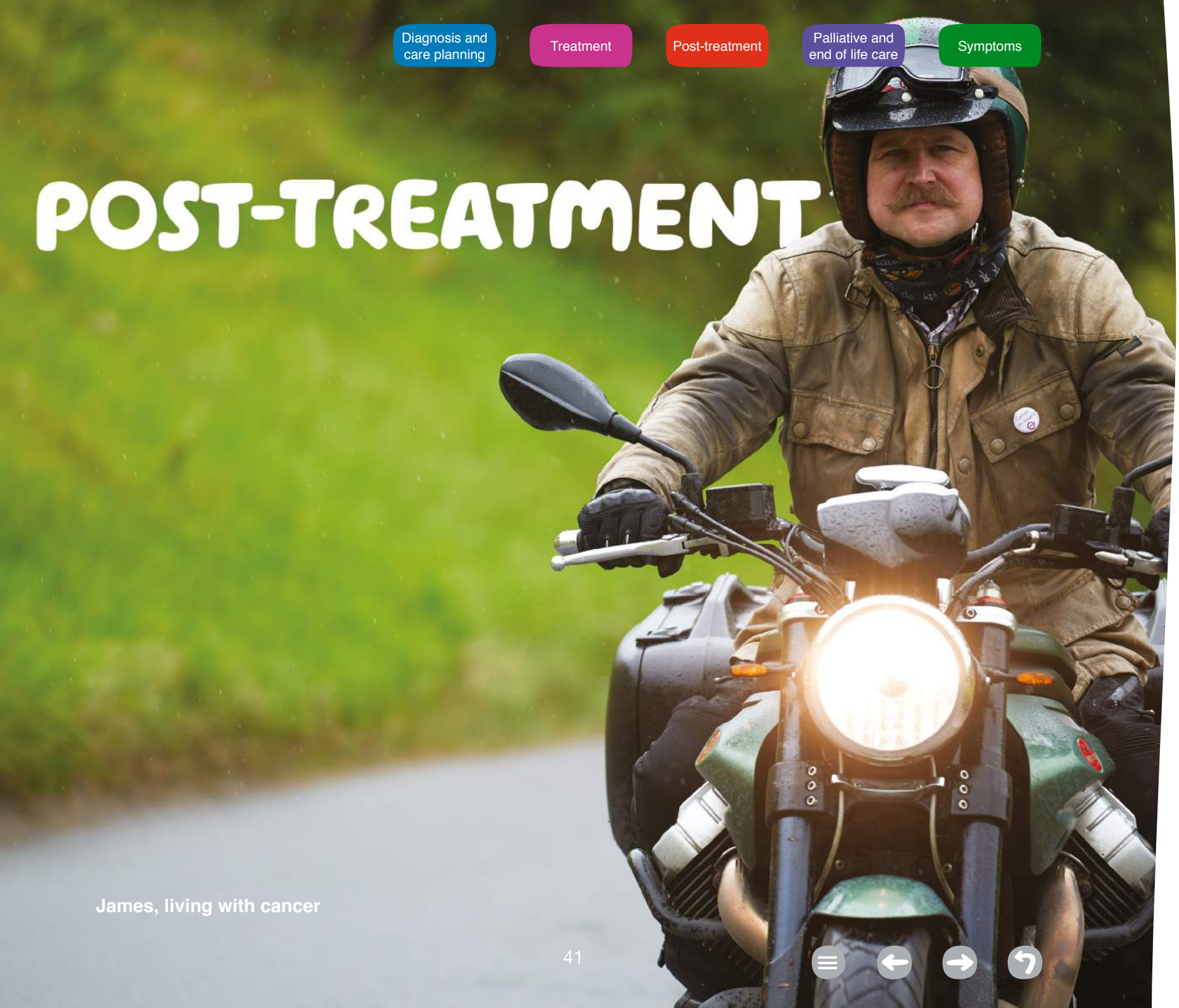
Generic

Treatment or referral

- Address issues regarding patients work/education including:
  1) Identify patient needs and goals around occupation.
  2) Provide vocational rehabilitation and advice on return to work as appropriate.
  3) Address any specific issues for teenage and young adult patients.
- Lifestyle management considering:
  1) Obtain information on social situation and support network.
  2) Screen for sexual functioning problems and refer on as necessary.
  3) Manage lifestyle adjustment including roles.
  4) Help maintain occupational activities that are meaningful to the patient, taking into account the influence of culture, religious beliefs and practices.
  5) Provide advise on maintaining function.
- Assess patients social needs as a client-led priority for teenage and young adult patients, ie engaging in hobbies, interests, learning to drive, etc.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

POST-TREATMENT



James, living with cancer

Assessment >
Activities of daily living >
Cognitive and psychological factors >
Communication >
Exercise >
Information/support >
Mobility and wellbeing >
Nutrition >
Referral/liaison >
Respiratory function >
Skin and soft tissue management >
Swallowing >


Diagnosis and care planning
Treatment
Post-treatment
Palliative and end of life care
Symptoms

Assessment

Generic

Assessment

- Provide Holistic Care Assessment of rehabilitation need and reassess needs on a regular basis considering:
  1) General assessment: independent functional status, quality of life and daily living, fatigue, anxiety and depression, mood and coping strategies, smoking and alcohol use, lifestyle.
- Assess and manage late effects from oncology treatment as symptoms present.
- Assess and manage cancer treatment effects where any functional or comorbidities affecting functional independence are identified.
- Undertake baseline assessment of physical fitness and review subsequently as required.
- Check for signs of recurrence/deteriorating symptoms.

Specific >

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Assessment (continued)

Specific

Assessment

- Undertake specialist assessments possibly specific to disease:
  1) Undertake cognitive assessment.
  2) Assess patient's circumstances and ability to act on advice.
  3) Undertake respiratory assessment and agree patient centred goals.
  4) Undertake mobility/muscle strength assessment and agree patient centred goals.
  5) Review communication and impact treatment or cognitive changes may have on this.
  6) Review swallowing and impact treatment may have
     - Perform instrumental assessments of the vocal tract including vocal fold function and voice when clinically appropriate
     - Perform instrumental assessments of dysphagia including videofluroscopy (vf) when clinically appropriate and/or fibre optic endoscopic examination (FEES) when clinically appropriate
  7) Carry out full holistic neurological assessment.
  8) Provide ongoing interventional assessment and therapeutic intervention for swallowing problems and communication disorders.
  9) Undertake assessment which includes Psychological status and mood.
- Assess patients to include the possibility of pathological fracture and spinal cord compression especially in cancers of the breast, lung, skin, prostrate, renal, ovarian, teenage and young adult sarcoma and myeloma.

Specific to breast

Assessment

Carry out 3–6 week post-op check up including measurement of limb circumference, progress of exercises, planning for radiotherapy and treatment of cording.

Specific to haematology

Assessment

- For teenage and young adult patients: assess patients for avascular necrosis. Assessment of pain in the joints (particularly weight bearing joints), altered range of movement, change in function due to joint problems. If suspected, liaise with treating team and ensure physiotherapist and occupational therapist referrals.

Monitoring/review

- Monitor degree of immune suppression.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Activities of daily living

Generic

Assessment

- Daily living activities including:
  1) Undertake assessment of domestic care ability.
  2) Undertake an environmental assessment (with or without patient present) and adaptations/ equipment where this is appropriate.
  3) Assess for and access compensatory strategies, adaptive techniques and equipment. Devise strategies to compensate for dysfunction and optimise independence, quality of life, self management of activities of daily living.
  4) Respond to variations in functional ability providing rehabilitation classes if required.
  5) Assess and respond to variations in functional ability focusing on mobility, transfers, personal activities of daily living, domestic activities of daily living such as driving, bathing, access to the toilet and cognition.
- Assess levels of fatigue and advise as necessary.
- Ensure aids and equipment to facilitate independence and/or care in activities of daily living is delivered and fitted prior to discharge according to local guidance including AMA (Amputee Mobility Aid) or PPAM Aid (Pneumatic Post Amputation Mobility Aid) for amputee patients.

Specific to brain

Treatment or referral

- Help with feeding, eating, self-care, washing, dressing, access and sign posting.
- Manage somnolence as a side effect of radiotherapy and be aware of impact on patient's physical.
- Manage side effects of long term steroid use.

Specific to gynaecology, colorectal, urology

- Assess and assist in management of incontinence.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Cognitive and psychological factors

Generic

Treatment or referral

- Assess, plan and engage in anxiety management programme in order to provide confidence for patient and/or carers in management of condition. Suggest coping strategies. Use cognitive behavioural therapy techniques where appropriate. Refer on to appropriate specialist if necessary.
- Identify psychological needs and offer up to level 2 psychological support throughout assessment and treatment and refer as necessary to psychological services and other support groups.
- Retrain in order to help patient with cognitive and perceptual dysfunction.
- Teach relaxation and structured sleep techniques.
- Manage mood through compensatory strategies.
- Discuss and help patients to explore their feelings around body image, self esteem, self-identity, confidence, sexuality and relationships.
- Assess and advise strategies to manage role adjustment and refer on to other agencies.
- Identify psycho-social needs to establish a base line measurement and promote psychological adjustment and goals setting related to loss of function.

Specific to breast, gynae

Treatment or referral

- Manage menopausal symptoms.

Specific to brain, haematology

Treatment or referral

- Assess and implement cognitive rehabilitation.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Communication

Specific to head and neck, lung, brain

Assessment

- Reassess communication status and needs on a regular basis (also considering cognitive impairment) to check for signs of recurrence and deteriorating symptoms and refer to medical/surgical teams if concerned.

Specific to head and neck

Assessment

- Liaise with work environment re communication needs and aids.
- Re-assess status of Surgical Voice Restoration (SVR).
- Carry out assessment at X-ray for voice problems with laryngectomy patients and advise re appropriateness of Botox injections.
- Undertake assessment (endoscopy) and treat any identified vocal cord palsy/dysfunction.

Specific to lung

Assessment

- Carry out assessment (endoscopy) and treatment of vocal cord palsy/dysfunction eg Thyroplasty medialisation procedures.

Specific to head and neck

Treatment or referral

- Change prosthesis when necessary and troubleshoot problems.
- Advise MDT on signs of recurrence or complications and provide appropriate advice and interventions.
- Continue oromotor range of motion, articulation and strengthening exercises to facilitate oral communication.

Specific to head and neck, lung

Treatment or referral

- Select, provide and maintain equipment and teach patients and carers appropriate use.

Specific to upper gastrointestinal, lung, breast, head and neck

Treatment or referral

- Initiate referral for vocal fold augmentation as appropriate.

Anorexia/cachexia/weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Exercise

Generic

Treatment or referral

- Provide advice and education on maintaining activity levels and fitness tailored to patient requirements including:
  1) Advise on general fitness programmes/home exercise to optimise physical condition and mobility.
  2) Provide general rehabilitation and exercise on prescription.
  3) Maintain functional therapy.
- Provide disease related exercise including:
  1) Provide exercises for neck, shoulder, facial, temporomandibular joint (TMJ) and relevant area of plastic reconstruction or surgery to ensure reduction in pain, return of movement and to improve function.
  2) Manage shoulder and chest wall problems.
  3) Physical and musculoskeletal problems that would lead to urinary/faecal incontinence.
  4) Assess and treat existing musculoskeletal problems such as joint range, weakness, pain.
- Help improve exercise tolerance by providing advice and education on maintaining (or increasing) physical activity levels to improve fitness and wellbeing – possibly through a general exercise programme or exercise classes.

Specific to gynae, colorectal, urology

Treatment or referral

- More intensive pelvic floor muscle training six months – three years after first treatment.

Specific to sarcoma

Treatment or referral

- For teenage and young adult patients: advise on changing exercise activities and adapting exercise habits following endoprosthetic replacement/ amputation.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Information/support

Generic

Treatment or referral

- Assess information needs for patients and provide suitable verbal and written advice, using information prescriptions if available.
- Provide and facilitate carer support, advice and information including referral to support groups using available media.
- Provide information and manage longer term effects of treatment
- Maintain awareness of wider issues of cancer prognosis.
- Liaise to provide financial support as appropriate.
- Ensure information for teenage and young adult patients is appropriate to their age.

Specific to breast, haematology, sarcoma, urology

Treatment or referral

- If metastatic bone disease, avascular necrosis or osteoporosis have been identified provide precautionary and preventative information about protecting vulnerable bones and improving exercise tolerance.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Mobility and wellbeing

Generic

Assessment

- Carry out mobility assessment including:
  1) mobility
  2) transfers
  3) personal assessment
  4) domestic activities of daily living
  5) environmental adaption needs
  6) provision of equipment including wheelchair
  7) assessment of postural management and seating.
- Undertake risk assessment for falls and manual handling and provide safety advice.

Treatment or referral

- Provide positioning and seating and postural advice in liaison with MDT as needs/symptoms require
- Advise patient and carers about effective lifting and general activity, (including use of equipment and techniques) or safe moving and handling. Provide written support materials if required.

Specific to colorectal

Treatment or referral

- Provide long-handled equipment such as shoehorns and sponges to minimise bending and twisting particularly if the patient is experiencing abdominal pain.

Specific to head and neck, breast

Treatment or referral

- Provide advice on scar management and posture.

Specific to lung, upper gastrointestinal

Treatment or referral

- Suggest non pharmacological intervention for pain management and nausea and vomiting.

Specific to sarcoma

Treatment or referral

- Ensure patients have rapid access to prosthetic services and amputee rehabilitation to ensure good limb fitting and functional mobility.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Nutrition

Generic

Assessment

- Nutritional assessment of the patient (where appropriate) to include:
  1) Review of current nutritional intake
  2) Current nutritional problems as a result of disease, symptoms or cancer treatment
  3) Degree of nutritional depletion and the likelihood of further nutritional depletion
  4) Nutritional implications of specific tumour types
  5) Physical state
  6) Current food and drink intake
  7) Anthropometric measurements
  8) Biochemistry
  9) Nutritional requirements (Energy, protein, fluid, electrolytes, micronutrients, fibre) using validated assessment tools and methods

Screening

- Implement nutritional screening – Screen all patients nutritionally at each outpatient, admission to hospital and/or in the community/primary care

Treatment or referral

- Devise an individualised nutritional care plan providing practical dietary advice tailored to the individuals needs, prognosis, symptoms, and circumstances and ensure interventions are commenced. Refer to other team members as appropriate.
- Where appropriate to the patients needs/diagnosis/ other conditions they may present with, provide relevant therapeutic dietary advice eg diabetes, coeliac, renal dysfunction (low potassium, low phosphate, sodium and fluid restrictions) as appropriate.
- Provide on-going advice and manage symptoms post treatment such as reflux, regurgitation, dumping syndrome, early satiety, poor appetite, nausea, vomiting, bloating and bowels, taste changes and mouth care, dysphagia, texture modification, diarrohoea.
- Advise on healthy eating, fatigue, weight Management and maintenance and alternative diets, vitamin, mineral and herbal supplements. Provide practical healthy eating advice in particular to those with a high BMI.
- Provide counselling on eating and drinking problems and perioperative feeding. Provide on-going dietetic monitoring and support to patient, family and carers/relatives.

Education

- Influence organisational approach to provision of food and drink.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Specific

Treatment or referral

- Where appropriate commence presurgical/ perioperative, and continue through treatment, oral/enteral/parenteral nutritional support to help improve quality of life:
  1) Provide advice on weaning from enteral tube feeding to oral diet
  2) Provide education regarding feeding tube management and the administration of feed
  3) Plan and Coordinate enteral feeding tube discharges and ensure referral to community services for continued support
  4) Liaise with home enteral feeding team for changes to feeding regime
  5) For patients requiring home total parenteral nutrition follow local guidelines
  6) Assess for timely removal and coordination of procedure for removal of the feeding tube

Specific to lung, head and neck, upper gastrointestinal

Treatment or referral

- Undertake joint dietetic and speech and language therapy assessments to manage longer term effects of treatment such as weight gain and swallowing problems.

Specific to upper gastrointestinal

Treatment or referral

- Advise on fat soluble vitamin if on PERT.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Post-treatment

Referral/liaison

Generic

Treatment or referral

- Advise and liaise with MDT including:
  1) Advise on signs of recurrence or complications and provide appropriate advice and interventions either as out patient or if readmitted
  2) Liaise with MDT – Communicate with relevant professionals involved in patient care and refer to other specialist professions such as OT, Physio, Psychology and Dietitian
  3) Contribute to discussion about ongoing treatment plan and make recommendations on any changes required
  4) Ensure AHP representation within the MDT clinic (acute or community based)
  5) Ensure appointments available in timely manner
  6) Liaise with other members of the team according to referral criteria and healthcare professionals in the oncology team and refer as necessary
- Refer to other Health Care Professional, team members, including extended team members, if appropriate and ensure access to ongoing support specifically required by patient. Specialists to provide advisory and educational role for other AHP staff.
- AHPs to liaise with keyworker and keyworker contact details provided. (AHPs may also be the keyworker.)
- As part of the discharge process, arrange outpatient or community rehabilitation services or palliative care and provide appropriate contact numbers to patients and family. Refer to support groups, self help group, expert patient programmes, Living With Cancer course.
- Undertake exit interview alerting patients of possible late effects and who to contact. Agree criteria for direct access or self-referral back into Rehabilitation Services.

Specific ›

Anorexia/cachexia/ weight loss ›
Breathlessness ›
Communication ›
Continence ›
Dysphagia ›
Fatigue ›
Lymphoedema ›
Metastatic spinal cord compression ›
Mobility ›
Pain ›

Specific

- For teenage and young adult patients: Refer to teenage and young adult specific post-treatment survivorship programme.

Specific to brain

Treatment or referral

- Refer to community/primary care teams and specialist neuro/cancer teams if available. They should also be referred to these teams throughout the pathway as care will transfer between community and acute settings dependant upon the patient's overall management. They may go home between treatments and there should be a smooth flow between acute/community teams to reflect this.

Specific to head and neck

Treatment or referral

- Provide speech and language therapist led clinic session.
- Screen for facial problems and refer to AHPs for assessment and management.

Specific to haematology

Treatment or referral

- For teenage and young adult patients: if avascular necrosis is suspected ensure referral for orthopaedic opinion.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Respiratory function

Generic

Treatment or referral

- Assess and maintain respiratory function managing respiratory problems including tracheostomy care and weaning.
- Provide pulmonary rehab pre and post surgery, chemotherapy and radiotherapy.

Specific to brain

- Splint to prevent deformities and control pain.

Specific to haematology

- Assess and monitor for signs of graft versus host disease (GVHD).

Skin and soft tissue management

Generic

Treatment or referral

- Assess for and arrange provision of pressure relieving cushions/mattresses to optimise comfort, support posture and minimise the risk of developing or exacerbating existing pressure sores.
- Assess, educate and advise on daily skin care.
- Provide advice on and undertake scar management and fibrosis.
- Assess skin integrity in pressure areas and refer for pressure relieving equipment if necessary.

Swallowing

Specific to lung

Treatment or referral

- Carry out assessment (endoscopy) and treatment of vocal cord palsy/dysfunction eg Thyroplasty medialisation procedures.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

Work and lifestyle

Generic

Treatment or referral

- Address issues regarding patients work/education including:
  1) Advise on maintaining role at work or re-engaging in work place
  2) Provide vocational rehabilitation as required
  3) Identify patients needs and goals around occupation/education
  4) Help patient return to work/education/voluntary work – discuss pacing to resume activities task analysis, work simplification and energy conservation to resume activities
  5) Address any specific issues for teenage and young adult patients
- Lifestyle management considering:
  1) Obtain information on social situation and support network
  2) Screen for sexual functioning problems and refer on as necessary
  3) Manage lifestyle adjustment including roles
  4) Help maintain occupational activities that are meaningful to the patient, taking into account the influence of culture, religious beliefs and practices
  5) Provide advise on maintaining function
- Support patients to re-engage in graded social activities.
- Assess patients social needs as a client-led priority for teenage and young adult patients, ie engaging in hobbies, interests, learning to drive, etc.
- Be aware that younger patients life changes are significant.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
Continence >
Dysphagia >
Fatigue >
Lymphoedema >
Metastatic spinal cord compression >
Mobility >
Pain >

PALLIATIVE AND END OF LIFE CARE

Sheena, Macmillan Clinical Nurse Specialist

Assessment >
Activities of daily living >
Cognitive and psychological factors >
Communication >
Exercise >
Information/support >
Mobility and wellbeing >
Nutrition >
Referral/liaison >
Respiratory function >
Skin and soft tissue management >

Assessment

Assessment

- Provide Holistic Care Assessment of rehabilitation need and reassess needs on a regular basis considering:

  General assessment:

  – independent functional status
  – quality of life and daily living
  – fatigue
  – anxiety and depression
  – mood and coping strategies
  – smoking and alcohol use
  – lifestyle.

- Undertake specialist assessments possibly specific to disease:

  1) Undertake comprehensive physical, social and functional assessment
  2) Undertake assessment of cognitive ability and psychological needs
  3) Provide ongoing assessment of quality of life, anxiety and depression, psychological and social needs as appropriate
  4) Provide ongoing assessment and feedback to multidisciplinary team about symptoms such as pain, breathlessness, fatigue, depression, low mood
  5) Assess and provide specialist and complex seating and/or positioning in bed

- Carry out mobility assessment including:

  1) mobility
  2) transfers
  3) personal assessment
  4) domestic activities of daily living
  5) environmental adaption needs
  6) provision of equipment including wheelchair and the need for hoists
  7) assessment of postural management and seating.

- Assess ability to communicate, make informed decisions and convey needs relating to pain, care, place of death and drawing up will.
- Assess patients to include the possibility of pathological fracture and spinal cord compression.

End of life

Treatment or referral

- Manage ascites as appropriate.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
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Pain >

Activities of daily life

Treatment or referral

- Assess and support patients independence in daily living activities including:
  1) Assess and advise on personal care and domestic activities
  2) Ensure treatable causes of fatigue are ruled out by referral to other disciplines
- Assess and assist in management of incontinence.
- Assess levels of fatigue and advise as necessary.
- Ensure aids and equipment to facilitate independence and/or care in activities of daily living is delivered and fitted prior to discharge according to local guidance including Amputee Mobility Aid (AMA) or PPAM Aid (Pneumatic Post Amputation Mobility Aid) for patients with amputations.

Cognitive and psychological factors

Treatment or referral

- Assess and plan and engage patient in an anxiety management programme and tailor to patients daily living and lifestyle, in order to provide confidence for patient and/or carers in management of condition.
- Identify psychological needs and offer up to level 2 psychological support throughout assessment and treatment and refer as necessary to psychological services and other support groups.
- Retrain and/or educate as necessary in order to help patient with cognitive and perceptual dysfunction.
- Teach relaxation and structured sleep techniques.
- Manage mood through compensatory strategies and engagement in meaningful activities.
- Discuss and help patients to explore their feelings around body image, self esteem, self-identity, confidence, sexuality and relationships.
- Provide ongoing psychological support with regards to adjusting to loss, deteriorating function, grief response.

End of life

Treatment or referral

- Undertake pre bereavement work with family.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
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Fatigue >
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Mobility >
Pain >

Communication

Treatment or referral

- Trial, prescribe and train in use of communication aids if required.
- Educate patient, carers and healthcare professionals on methods to provide optimal communication function.

Exercise

Treatment or referral

- Advise on pacing, relaxation and controlled exercise.
- Advise on and provide exercise and physical activities to help maintain/improve physical and psychological functioning and quality of life taking into account variations in health status.

Anorexia/cachexia/ weight loss >
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Pain >

Information/support

Treatment or referral

- Assess information needs for patients and provide suitable verbal and written advice, using information prescriptions if available.
- Provide and facilitate carer support, advice and information including referral to support groups using available media.
- Enable informed decision making with regards to treatment, management and place of care (preferred place of dying). Where this is home help facilitate any modifications.
- Consider ethical issues and aims of treatment to improve quality of life.
- Consider sudden events, scenario planning.
- Ensure information for teenage and young adult patients is appropriate to their age.

End of life

Treatment or referral

- With the MDT/key worker, identify the dying process and implement Liverpool Care Pathway ensuring that unnecessary and invasive treatment is avoided.

Mobility and wellbeing

Assessment

- Undertake risk assessment for falls and manual handling and provide safety advice.

Treatment or referral

- Where necessary, assess, advise and implement positioning and seating and postural advice in liaison with MDT as needs/symptoms require.
- Provide aids/equipment to support daily living and self management techniques to optimise management of activities of daily living and deteriorating function.
- If metastatic spinal cord compression is suspected, stabilise/immobilise unstable spinal areas using braces, splints and positioning.
- Prevent complications of inactivity such as pressure sores and chest infection. Suggest non pharmacological intervention for pain management and nausea and vomiting.

Anorexia/cachexia/ weight loss >
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Pain >

Nutrition

Assessment

- Nutritional assessment of the patient (where appropriate) to include:
  1) Review of current nutritional intake
  2) Current nutritional problems as a result of disease, symptoms or cancer treatment
  3) Degree of nutritional depletion and the likelihood of further nutritional depletion
  4) Nutritional implications of specific tumour types
  5) Physical state
  6) Current food and drink intake
  7) Anthropometric measurements
  8) Biochemistry
  9) Nutritional requirements (Energy, protein, fluid, electrolytes, micronutrients, fibre) using validated assessment tools and methods

Screening

- Implement nutritional screening – Screen all patients nutritionally at each outpatient, admission to hospital and/or in the community/primary care.

Treatment or referral

- Devise an individualised nutritional care plan providing practical dietary advice tailored to the individuals needs, prognosis, symptoms, and circumstances and ensure interventions are commenced. Refer to other team members as appropriate.
- Where appropriate to the patients needs/diagnosis/other conditions they may present with, provide relevant therapeutic dietary advice eg diabetes, coeliac, renal dysfunction (low potassium, low phosphate, sodium and fluid restrictions) as appropriate.
- Provide on-going advice and manage symptoms post treatment such as reflux, regurgitation, dumping syndrome, early satiety, poor appetite, nausea, vomiting, bloating and bowels, taste changes and mouth care, dysphagia, texture modification, diarrohoea.
- Where appropriate commence oral/enteral/parenteral nutritional support to help improve quality of life:
  1) Provide advice on weaning from enteral tube feeding to oral diet
  2) Provide education regarding feeding tube management and the administration of feed
  3) Plan and coordinate enteral feeding tube discharges and ensure referral to community services for continued support
  4) Liaise with home enteral feeding team for changes to feeding regime

Anorexia/cachexia/weight loss >
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Palliative and end of life care

Nutrition (continued)

5) For patients requiring home total parenteral nutrition follow local guidelines
6) Assess for timely removal and coordination of procedure for removal of the feeding tube
7) Make decisions with multi-disciplinary team around ethics for feeding and feeding withdrawal.

- Provide counselling on eating and drinking problems and perioperative feeding. Provide on-going dietetic monitoring and support to patient, family and carers/ relatives. Work with family on understanding of and anxiety about eating and drinking.

Education

- Influence organisational approach to provision of food and drink.

Anorexia/cachexia/ weight loss >
Breathlessness >
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Pain >

Referral/liaison

Treatment or referral

- Advise and liaise with MDT including
  1) Liaise with MDT – Communicate with relevant professionals involved in patient care and refer to other specialist professions such as OT, Physio, Psychology and Dietitian
  2) Contribute to discussion about ongoing treatment plan and make recommendations on any changes required
  3) Ensure AHP representation within the MDT clinic (acute or community based)
  4) Liaise with other members of the team according to referral criteria and healthcare professionals in the oncology team and refer as necessary
- Ensure good communication and coordination as the patient transfers between the various care settings and professions.
- AHPs to liaise with keyworker and keyworker contact details provided. (AHPs may also be the keyworker.)
- Refer to support groups, self help group, expert patient programmes, Living With Cancer course.
- Signpost to other supportive care services as required dependent on need.
- Be aware of progression of symptoms and the need for further palliative or surgical intervention such as paracentesis, stenting and debulking and how this further affects quality of life.

End of life

- Ensure appropriate withdrawal of intervention in liaison with multidisciplinary team.

Anorexia/cachexia/ weight loss >
Breathlessness >
Communication >
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Fatigue >
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Pain >

Respiratory function

Treatment or referral

- Maintain optimal respiratory function and airway management using exercise and sputum clearance techniques.
- Provide non-pharmacological management of breathlessness.

Skin and soft tissue management

Treatment or referral

- Assess for and arrange provision of pressure relieving cushions/mattresses to optimise comfort, support posture and minimise the risk of developing or exacerbating existing pressure sores.
- Advise and encourage on mouth care strategies to reduce the use of artificial hydration.
- Manage sensory impairment advising on suitable clothing.
- Assess positioning and provide simple massage/ movement/comfort measures clothing.
- Manage tissue viability, lymphoedema and lymphorrhoea as appropriate and refer as necessary to other services.

Work and lifestyle

Treatment or referral

- Address issues regarding patients work/education including:
  1) Assess and advise on occupational pursuits
  2) Address any specific issues for teenage and young adult patients
- Lifestyle management considering:
  1) Work with patient to achieve lifestyle management with role adjustment, loss and self esteem
  2) Obtain information on social situation and support network
  3) Screen for sexual functioning problems and refer on as necessary
  4) Help maintain occupational activities that are meaningful to the patient, taking into account the influence of culture, religious beliefs and practices
  5) Provide advise on maintaining function

Anorexia/cachexia/ weight loss >
Breathlessness >
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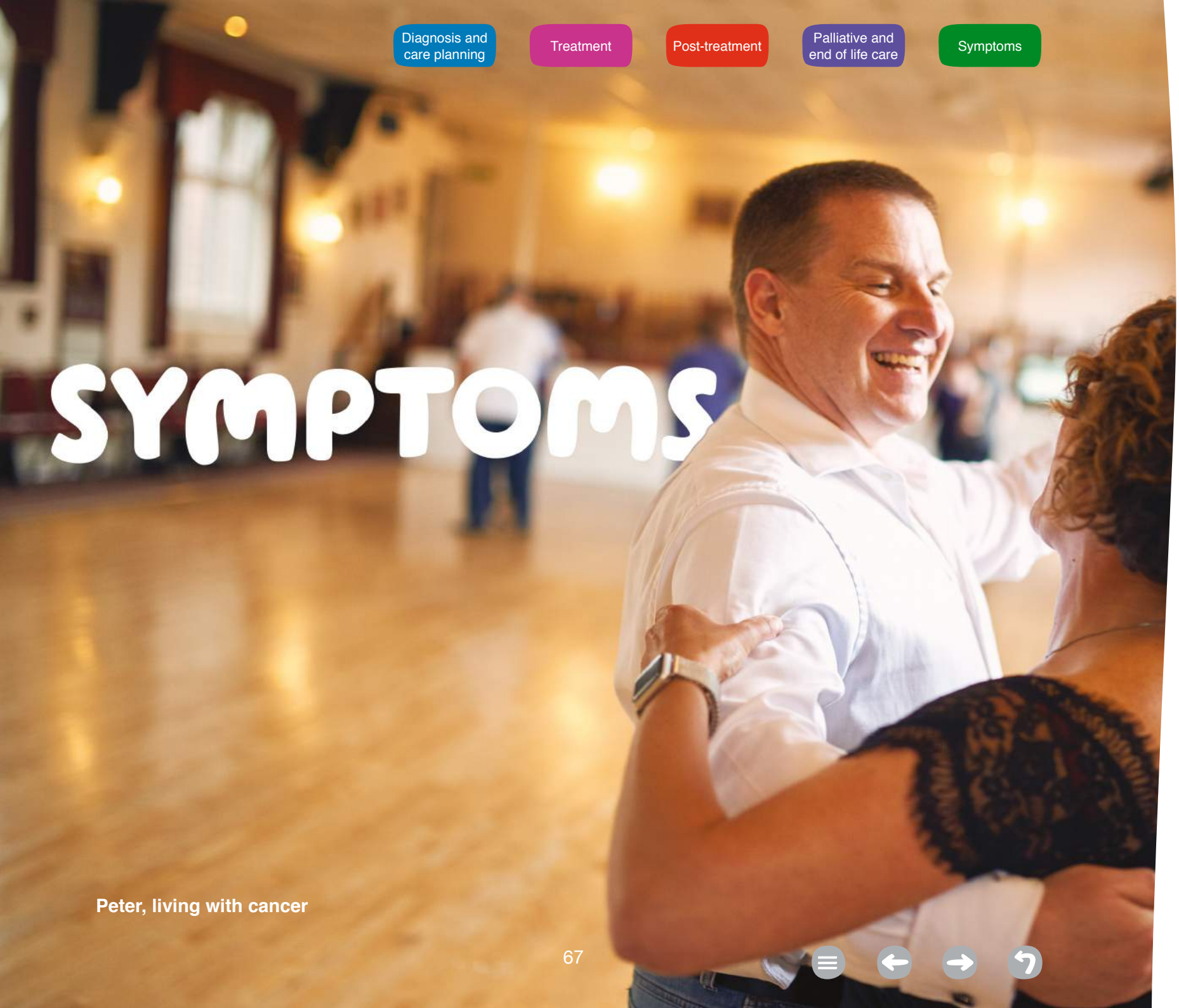
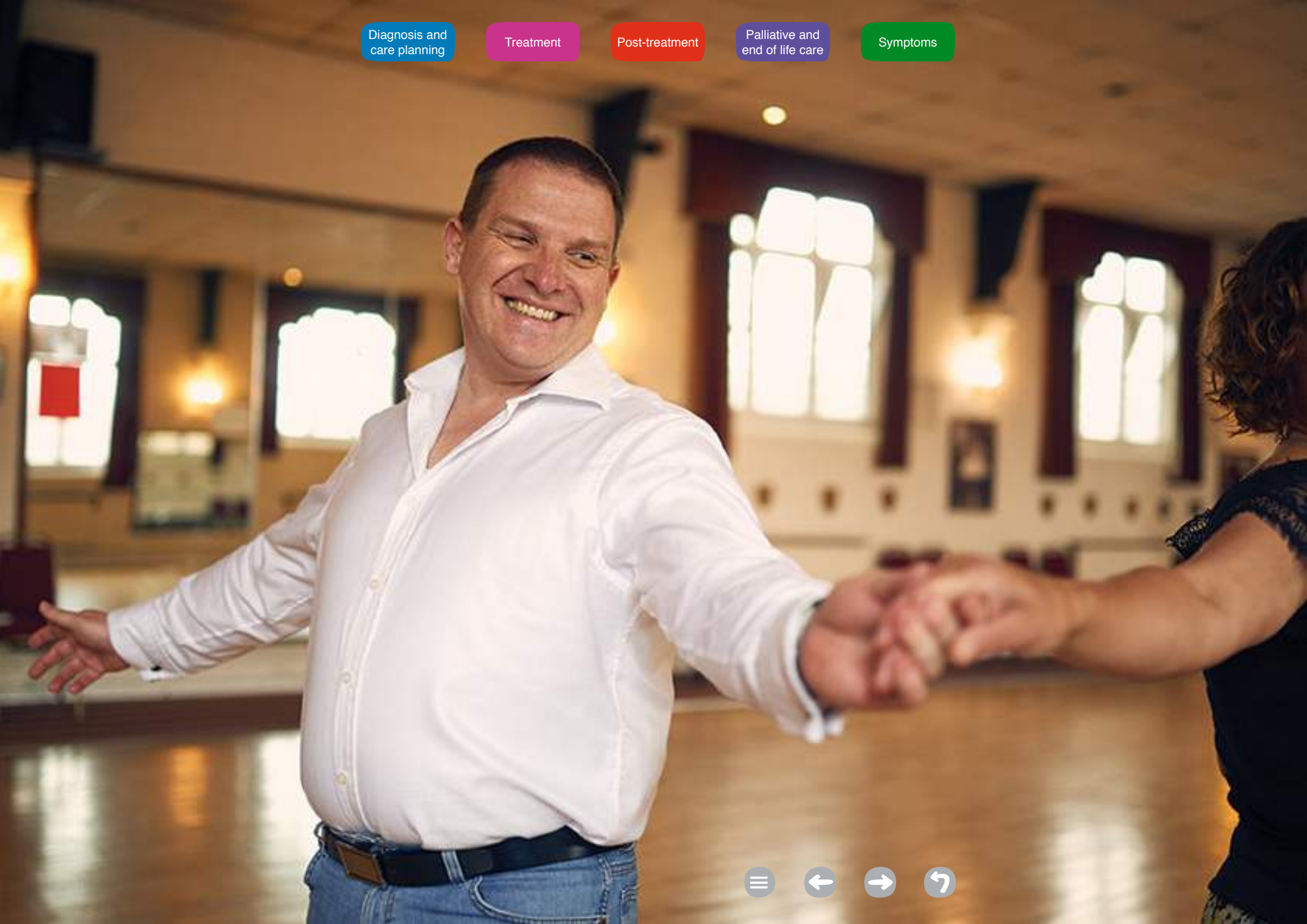


SYMPTOMS

Peter, living with cancer


Diagnosis and care planning
Treatment
Post-treatment
Palliative and end of life care
Symptoms

Assessment

- Nutritionally screen initially for malnutrition to establish baseline for pathway.
- Carry out in depth assessment of nutritional need
- Review any existing screening/assessments undertaken.
- Communicate with MDT for management plan.
- Establish case history, current extent of disease and proposed form of treatment.
- Present patient at MDT.
- Liaise with previous AHPs/social colleagues involved.
- Undertake detailed dietary assessment to include anthropometric and biochemical measurements.
- Influence organisational approach to provision of food.
- Establish case history, current extent of disease and proposed form of treatment.
- Liaise with previous AHPs/social colleagues involved.
- Assess for body image alteration/adjustment.
- Screen for sexual function problems and refer on as necessary.
- Establish soft tissue patency needs.
- Assess functional ability relating to activity stamina, food preparation and eating.

Treatment or referral

- Recognise signs of anxiety/depression and provide anxiety management as appropriate.
- Agree realistic goals with patient and carers to include quality of life.
- Identify nutritionally related symptoms resulting in weight loss/anorexia/cachexia.
- Offer dietetic advice for management of these symptoms:
  - taste changes
  - dry mouth
  - oral problems
  - nausea
  - vomiting
  - diarrhoea
  - constipation
  - malabsorption
  - weakness
  - loss of appetite
  - early satiety
  - weight loss
  - gastrointestinal disturbances
  - bowel obstruction
  - reflux
- Consider/manage oral nutritional supplements both non prescribable and prescribable.
- Consider pharmaceutical agents eg appetite stimulants, steroids, pancreatic enzymes, proteinetics.
- Consider/manage enteral/parenteral nutritional support.
- Refer to other services/agencies as appropriate.
- Give written information for patient and carers about access and referral to other appropriate agencies.
- Influence organisational approach to provision of food.
- Provide exercise advice and treatment to maintain muscle bulk, improve stamina and functional ability.
- Advise on exercise regime and activity tolerance.
- Consider body image adjustment and psychological concerns.
- Consider relaxation.
- Consider visualisation.
- Consider distraction therapy.
- Assess and address issues around meals, timings and preparation, weakness and pressure care and equipment provision.

Anorexia/cachexia/weight loss

Treatment or referral (continued)

- Provide food preparation help – from shopping to cooking.
- Refer to other services/agencies as appropriate.
- Provide support with clothing.
- Consider body image adjustment.
- Assess and address issues around meals, timings and preparation, weakness and pressure care and equipment provision.
- Consider appropriateness of interventions.
- Discuss realistic goals with patient and carers looking at quality of life issues.
- Discuss with multi-disciplinary/Palliative Care Team.
- Withdraw nutritional supplements/artificial feeding if appropriate.
- Influence organisational approach to provision of food.

Monitoring/review

- Undertake reassessment at each key point in pathway.
- Review planned interventions at each key point in pathway.
- Provide ongoing communication with MDT and other services/agencies.
- Consider timeliness of interventions.
- Discharge as appropriate.
- Refer to community Dietitian for ongoing monitoring and review post discharge.
- Provide details of how to refer back to acute service if required.
- Influence organisational approach to provision of food.
- Consider body image adjustment.
- Assess and address issues around meals, timings and preparation, weakness and pressure care and equipment provision.

Assessment

- Identify reversible causes.
- Assess breathlessness severity using validated tool such as BORG (Gunner Borg) to determine outcome scale which measures rate of perceived exertion.
- Assess knowledge of patient and their capacity to self manage.
- Assess severity of breathlessness and frequency and timing.
- Determine factors which currently exacerbate or ease the breathlessness.
- Refer on as necessary to other members of the multidisciplinary team.
- Assess contributory factors to breathlessness eg pain, retained secretions.
- Assess general appearance, auscultation and palpation.
- Assess functional and psychological impact of breathlessness.
- Screen for hyperventilation syndrome if suspected.
- Assess oxygen saturation levels and need for home oxygen.
- Assess use of respiratory medication such as inhalers and nebulisers.
- Assess and score activities of daily living and patient's current problems.
- Assess anxiety.
- Screen nutrition status.
- Assess nutritional status, intake and agree interventions and care plan.
- Liaise with MDT members and refer on as necessary.

Treatment or referral

Clinicians will require a detailed knowledge of anatomy and physiology to undertake the following:

Consider and act on the following:

- Position of ease.
- Breathing control techniques/breathing retraining such as pursed lip breathing, box breathing and diaphragmatic breathing.
- Advise on pacing, prioritising and planning.
- Referral to Wheelchair Services for wheelchair assessment and provision.
- Education of patient and carers.
- Provision of patient information.
- General advice and support.
- Setting SMART goals – specific, measurable, accurate, realistic and timely.
- Exercise prescription.
- Need for mobility aids.
- Respiratory mucociliary chest clearance techniques.
- Increase air flow – eg use of fan.
- Pulmonary rehabilitation (if appropriate).
- Advice about use of oxygen.
- Review of respiratory medication such as checking technique when using inhaler, converting to nebulized therapy if appropriate.
- Provide advice on or request other pharmacological interventions (eg opioids).
- Equipment provision.
- Home visits.
- Anxiety management techniques.
- Minor and major home adaptations.
- Role retraining.
- Assess functional ability to feed.
- Assess nutrition status, intake, intervention, care plan.
- Commence nutrition support including oral supplements and food fortification.
- Liaise with MDT members.
- Refer on to Breathlessness team, key worker and other AHP's.

Monitoring/review

- Ensure use of appropriate outcome measures such as MRC (Medical Research Council) breathlessness scale, quality of life measures, exercise tolerance.
- Consider the following:
  - Position of ease
  - Breathing retraining
  - Pacing, prioritising and planning
  - Wheelchair assessment and provision
  - Education of patient and carers
  - Provide patient information
  - General advice and support
  - Individual goal setting
  - Agree case management
  - Nutritional status
- Consider patient self-management and provision of contact details for re-accessing rehab services.
- Patient choice regarding telephone or face-to-face review and agree follow up options.
- Refer appropriately on to other services.
- Determine frequency of:
  - Ongoing monitoring
  - Communicate plan and outcome interventions with MDT and relevant agencies
  - Provide support to family/carers through end of life care
  - Regular review of equipment needs

The majority of the breathlessness pathway will be carried out by Physiotherapists, Occupational Therapists and Nurses with some input from Speech and Language Therapist and Dietitians.

Communication

Assessment

- Establish need for interpreter.
- Liaise with previous AHP's, social services and community colleagues and provide AHP differential diagnosis.
- Establish case history, current extent of disease and proposed form of treatment.
- Carry out initial assessment including:
  - oro-facial/laryngeal motor evaluation
  - assessment of receptive – auditory and visual
  - assessment of receptive language-auditory and reading
  - assessment of expressive language – verbal and written
  - assessment of speech production including fluency
- Speech and language therapy involvement in intraoperative evaluation of language function, if appropriate.
- Carry out assessment of cognition and it's impact on communication including insight and awareness.
- Involve inclusion of communication partners in assessment.
- Complete assessment of non verbal communication.
- Carry out assessment of environmental factors impacting on communication.
- Undertake assessment of communication needs.
- Carry out joint assessments, as appropriate with other professionals.
- Contribute to decision making regarding capacity to consent.
- Assess impact of medical status on communication impairment including level of arousal.
- Consider impact of medication/treatment on communication impairment.
- Establish patient perspective on communication.
- Provide initial speech and language therapy diagnosis and/or summary of findings to patient, communication partner and healthcare professionals.
- Advise medical staff on proposed treatment plan.

Communication

Identification of risk

- Identify at risk patients.
- Educate other professionals on alerts for communication impairment.
- Refer at risk patient to Speech and Language Therapist (SALT).

Treatment or referral

- Educate patient, communication partners, appropriate health and social care professionals on patient specific communication difficulties.
- Refer onto other agencies and professionals as appropriate.
- Consider co-morbidities and provide strategies to compensate for immediate communication issues.
- Refer onto specialist Augmentative and Alternative Communication (AAC) services for assistive devices as appropriate.
- Investigate funding for AAC as appropriate.
- Provide psychological support and refer on where appropriate.
- Facilitate contacts with other patients as appropriate.
- Refer patient and/or communication partner to local support groups.
- Advocate for patient as appropriate.
- Establish patient-led realistic communication goals with consideration of World Health Organisation model – impairment/activity/participation.
- Agree a goal orientated treatment plan and provide recognised interventions for specific communication differential diagnosis within the context of diagnosis and prognosis.
- Dysphonia.
- Dysarthria.
- Apraxia.
- Cognitive communication.
- Acquired dysfluency.
- Provide these interventions as appropriate to patient, communication partner, health and social professionals.
- Continue education, support and advocacy throughout the pathway.
- Provide specialist support for professional colleagues.

Communication

Monitoring/review

- Review goals and interventions in the light of changing circumstances.
- Review effectiveness of treatment.
- Continually re-assess patient and their communication skills and treat accordingly in response to changes in presentation, medical treatment, disease progression and response to medication.
- Alert MDT or consultant to any change in patient presentation including improvement or deterioration.
- Review and monitor patient and consider discharge if no further direct intervention is indicated.
- Ensure a mechanism is in place for re-referral.

The majority of interventions on the Communication Difficulties care pathway will be carried out by Speech and Language Therapists.

Assessment

Surgery

- Assess for dimensions of incontinence such as:
  - Awareness of incontinence
  - Type of urinary incontinence for example urge urinary incontinence, functional incontinence and nocturnal enuresis
  - Nocturia
  - Fluid balance
  - Anal incontinence – flatus/type of stool
  - Activities of daily living
  - Knowledge of access to toilet
  - Ability to get to toilet and undress etc
  - Is assistance available to help get to the toilet or to have a commode when needed?
  - Can the patient access a call bell, or let the staff know when toileting is required?
  - Assess current fitness and exercise levels and evidence of decreased activity and physical fitness
  - Pain
  - Current disease status and treatment. Identification other constraints such as bone metastases, neutropenia etc
  - Medication
  - Relationships
  - Patient perspective
  - Mood eg depression
  - Other relevant symptoms
  - Cognition and perception
  - Other comorbidities
- Refer on as appropriate.
- Influence organisational approach to provision of appropriate toileting.

Radiotherapy

- Assess for dimensions of bladder and bowel dysfunction such as:
  - Urinary or faecal urgency leading to incontinence
  - Frequency of passing urine or stool
  - Medication
  - Relationships
  - Sexual dysfunction
  - Patient perspective
  - Mood eg depression
  - Other relevant symptoms
  - Cognition and perception
  - Other comorbidities

Screening

- Screen for possible causes for example urinary tract infection.
- Assess patient's ability to access commode or toilet.
- Following removal of catheter, be aware of the possibility of bladder overfill if bladder fails to empty.
- Be aware of implications on the urethral sphincters of long-term in-dwelling urethral catheters.
- Urological, gynaecological and prostate surgery to the pelvic area is more likely to affect urinary control.
- Surgery affecting the anal sphincter and bowel may affect faecal continence.
- Radiotherapy to the pelvic area may cause temporary or sometimes permanent bladder and bowel and sexual dysfunction.

Identification of risk

An average prevalence of continence problems of one in three women and one in four men is often quoted, which increase with age, but it is not an inevitable progression.

Continence depends on:

- Cortical awareness.
- Intact sphincteric control (muscular and neural).
- Intact spinal pathways (brain S2 S3).
- Intact physiological urinary and bowel systems.
- Mobility to get to a toilet, dexterity to undress.
- Patients identified through a multidisciplinary approach such as the Holistic Care Assessment.
- Initial treatment intervention is based on containment which is essential to avoid skin breakdown. Provision of pads or catheters may be required.

Continence

Treatment or referral

- If patient showing untreatable, resistant and/or recurrent symptoms, refer for specialist review and management to a continence specialist.
- Influence organisational approach to accessibility of toilets.
- Refer to dietitian for faecal incontinence following bowel surgery.

Consider the following:

- Improve accessibility to toilet such as moving bed nearer, providing better signage and raised seating.
- Assessment for and provision of containment products.
- Fluid. Provide advice on taking sufficient quantities, avoiding caffeine and alcohol if urgency is troublesome. Discuss use of diuretics.
- Provide advice on adapting clothing.
- Provide nutritional advice and discuss adapting diet.
- Provide exercise programme aimed at muscle strengthening (including pelvic floor) and improving mobility.
- Discuss possible side-effects of medication such as constipation.
- Discuss medication to help urgency (anti-muscarine) and cranberry juice to help urinary tract infection prevention/bladder irritation.
- Consider use of acupuncture to help bladder irritation.
- Consider location and setting.
- Identify carer needs and enable or empower them to achieve goals.
- Refer on or signpost to other relevant services as appropriate.
- Consider respite or continuing care.
- Influence organisational approach to the provision of food.

Education

- Provide access to relevant and timely information. Discuss and reinforce this with patient and carer as appropriate.
- Provide written information including continence strategies (may need different language and formats).
- Provide information on impact of disease and treatment.
- Direct and signpost to other services available as appropriate for needs. Also charities such as the Bowel and Bladder Foundation and Promocon which will provide information for patients and carers specific to incontinence.
- Influence organisational approach to provision of accessible toileting facilities.

Monitoring/review

- Re-assess continence status as appropriate.
- Set realistic goals.
- Identify key worker where appropriate.
- Facilitate self management and provide self management strategy.
- Influence organisational approach to provision of adequate coping and/or toilet facilities where this is appropriate to help self-management strategies.

Dysphagia

Assessment

- Carry out nutritional screening for malnutrition.
- Review any existing screening and undertake assessments.
- Communicate with MDT for management plan.
- Establish case history, current extent of disease and proposed form of treatment.
- Present patient at MDT. Discuss ethical issues/ quality of life and potential feeding routes.
- Liaise with professional colleagues.
- Carry out detailed dietary assessment including assessment of current intake, nutritional status, functional capacity, biochemical markers and potential for further problems. Assessment of other symptoms which may affect nutritional intake.
- Carry out simple swallowing screen.
- Influence organisational approach to provision of food.
- Refer to other services and agencies as appropriate.
- Carry out diagnostic swallow assessment.
- Undertake assessment of swallowing related quality of life issues with standardised assessment.
- Carry out clinical/bedside swallow assessment.
- Assessment of swallow.
- Advise patient on diet modification and swallow manoeuvres to facilitate oral nutrition as appropriate.
- Provide specialist equipment.
- Liaise with professional colleagues.
- Provide prophylactic dysphagia therapy programme for maintenance of swallow function during treatment.
- Provide information to patient and MDT on diagnostic findings and recommendations for treatment.
- Inform patient of treatment planning process – discussion with patient and MDT on effects of cancer and planned treatment on eating and drinking, feeding options/risk management and quality of life issues.
- Inform on treatment planning process – information to patient/carers and MDT re likely.

Dysphagia

Treatment or referral

- Agree realistic goals with patient and carers to include quality of life.
- Consider and manage texture, energy and modification of diet.
- Consider and manage oral nutritional supplements both non prescribable and prescribable.
- Consider and manage prophylactic nutritional support.
- Consider and manage enteral and parenteral nutritional support.
- Consider and manage dietary management of comorbidities.
- Refer to other services and agencies as appropriate.
- Assess impact of interventions on quality of life.
- Give written information for patient and carers.
- Manage, in liaison with the MDT, acute and chronic side effects of oncological treatment that impact on swallowing.
- Provide support together with the MDT on tracheostomy management and weaning.

Surgery

- Work with the MDT on tracheostomy management and weaning.
- Monitor swallow function post surgery and reassess as appropriate.

Radiotherapy/chemotherapy.

- Monitor swallow function pre treatment and regularly during treatment and reassess as appropriate.
- Carry out bedside swallow assessment.
- Undertake instrumental assessment of swallow.
- Monitor ongoing recommendations on diet modification and swallow manoeuvres.
- Devise and monitor appropriate swallow rehabilitation therapy following assessment findings.
- Provide specialist equipment.
- Liaise with professional colleagues on patient's current swallow status and feeding needs.
- Access specialist skills from other disciplines to assist in management of swallow function.
- Devise and monitor appropriate swallow rehabilitation exercises.
- Alert MDT to new symptoms or signs of deterioration.

Dysphagia

Treatment or referral (continued)

- Provide regular assessment and support during treatment to monitor subtle changes in swallow function and manage symptoms of the treatment that may impact on swallowing with aim of maintaining safe oral nutrition as much as possible. This may include repeated instrumental assessments.
- Assess for and manage aspiration.
- Undertake respiratory status assessment.
- Provide treatment of respiratory problems as indicated with active cycle breathing techniques (ACBT), mobilisation, manual hyperinflation/IPPB, manual techniques, breathing control and oxygen/ nebulisers as prescribed by medics.
- Provide emergency on-call service (24/7).
- Assess and manage range of movement – temporo mandibular joint, head, shoulder and neck.
- Assess cause and severity and treat as appropriate.
- Provide breathing control oxygen therapy (needs to be prescribed by doctor).
- Offer advice on positioning and posture.
- Consider appropriateness of interventions.
- Discuss realistic goals with patient and carers including quality of life issues.
- Discuss with MDT and Palliative Care Team.
- Withdraw nutritional supplements and artificial feeding if appropriate.
- Support patients and carers to facilitate withdrawal of nutritional support.
- Consider quality of life and ethical issues related to continuing or withdrawing nutritional support.
- Support patient choice in dysphagia management and risks at end of life.
- Provide Information on dysphagia and aspiration in the context of end of life.
- Consider quality of life and ethical issues related to interventions and eating and drinking functions.
- Monitor swallowing function and recommend management strategies to support continued oral nutrition.
- Discuss realistic goals with patient and carers including quality of life and ethical issues related to interventions.
- Discuss with MDT/Palliative Care team options for nutritional intake.

Interventions in the Dysphagia pathway will mostly be carried out by speech and language therapists and dietitians.

Dysphagia

Monitoring/review

- Reassess and review planned interventions at each key point in pathway.
- Manage long term nutritional status and intake as impacted upon by dysphagia.
- Manage practical feeding tube and long term artificial feeding.
- Ensure ongoing communication with MDT and other services and agencies.
- Address any issues with social eating.
- Consider timeliness of interventions.
- Discharge as appropriate.
- Refer to community dietitian for ongoing monitoring and review post discharge.
- Provide details of how to refer back to acute service if required.
- Monitor swallow function and reassess as appropriate.
- Devise and monitor appropriate swallow rehabilitation therapy following assessment findings.
- Monitor ongoing recommendations on diet modification and swallow manoeuvres.
- Liaise with professional colleagues on: patient's current swallow status and feeding needs.
- Access specialist skills from other disciplines to assist in management of swallow function.
- Alert MDT to new symptoms or signs of deterioration.
- Provide ongoing care and support for respiratory problems and tracheostomy.
- Provide exercise rehabilitation for deconditioning.

Assessment

- Assess for dimensions of fatigue, such as:
  - Fatigue patterns including onset and duration
  - Sleep
  - Nutrition
  - Activities of daily living
  - Physical and physiological assessment
  - Current fitness and exercise levels including evidence of decreased activity and physical fitness
  - Pain
  - Current disease status, treatment identification and other constraints such as bone metastases and neutropenia
  - Medication
  - Mood
  - Cognition and perception
  - Relationships
  - Patient perspective
  - Vocational life
  - Family life
  - Social life
  - Other relevant symptoms
  - Other comorbidities
- Refer on as appropriate.

Screening

- First screen for treatable causes such as anaemia, hypothyroidism, depression, anxiety, weight loss, pain, medication side effects, infection, anorexia, malabsorption and other comorbidities.

Fatigue

Identification of risk

- Patient experiences excessive tiredness which impacts on their daily life. This could be during or following treatment, last for weeks, months or even years, or may be a symptom of the disease itself.

Fatigue

Treatment and referral

- If showing untreatable, resistant or recurrent symptoms, and scoring above 3 on a 1–10 scale, (0 being no fatigue, 10 being worst possible) refer for specialist review management. Those scoring 3 or below should receive written information only but be reassessed as required.
- Agree realistic goals with patient.
- Relaxation and sleep techniques.
- Energy conservation, pacing and compensatory techniques.
- Anxiety and stress management.
- Provide equipment as needed.
- Environmental adaptation.
- Enhancing activity.
- Exercise programme aimed at improving mobility, strength and stamina. Will include cardio-vascular work and muscle strengthening programme.
- Psychological therapy of cognitive behavioural therapy/hypnosis.
- Nutritional support and advice.
- Acupuncture and complementary therapies.
- Sleep hygiene.
- Cognitive support.
- Medical assessment and re-assessment.
- Consider group or individual setting.
- Consider vocational rehabilitation.
- Identify carer needs.
- Refer on as appropriate.
- Signpost to support groups.
- Enable/empower.
- Consider respite or continuing care.

Education

- Provide access to relevant and timely information.
- Reinforce information about fatigue.
- Provide written information including exercise programme for home use (language and format).
- Provide information on impact of disease and treatment.

Monitoring/review

- Appropriately reassess and refer on multidisciplinary working including reassessment of exercises and progression where appropriate.
- Agree realistic goals with patient.
- Identify key worker where appropriate.
- Facilitate self management.
- Provide self management strategy.
- Re assess when/if appropriate.

Interventions in the fatigue/energy management care pathway will be mostly carried out by physiotherapists, occupational therapists and dietitians.

Assessment

- Carry out pre-op screening and assessment including limb circumference and medical history.
- Provide pre-op information, obtain consent, advise patient of risk of lymphoedema and strategies which will help to reduce risk. Early access to treatment can help to prevent the complex condition developing.

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.

- Ensure thorough investigation to identify cause and make aware they may need medical management prior to, or concurrent.
- Assessment techniques may need to be modified and individual treatments selected to ease specific symptoms and suited to patient and carer.
- 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 and trained at the appropriate level.

Identification of risk

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.

At risk patients should be:

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

Education and screening could be provided by a skilled healthcare technician (Agenda for Change Band 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 lymphedema 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.

Lymphoedema

Treatment or referral

- Provide information prescription and identify Keyworker.
- Teach self-management and care of affected (or potentially affected) limb/quadrant.
- Repeat screening technique and give preventative advice and symptom warning with contact details.
- Reiterate preventative advice 6–8 weeks post op (oncology/surgical teams).
- Provide reconstructive advice – patients undergoing reconstruction also need preventative advice and may be at risk of developing lymphoedema in back/abdomen due to surgery.
- Chemotherapy – provide advice on prevention to protect against damage to at risk limb and warn of potential of oedema as direct side effect of treatment.
- 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.
- At risk treatment areas – If patient has had radiotherapy to the following areas, their risk of lymphoedema is higher:
  - Aupper limb – head and/or neck region, supra clavicular fossa or axilliary area
  - Alower limb – pelvic area

  Therefore, provide regular limb volume screening for early detection of symptoms (gold standard)/and encourage patient to self report symptom.
- Advise on recommended exercises, positioning and skincare measures.
- If additional tests/information are required these can be requested from the referrer GP/Medical Consultant (ie cancer treatment history, scans, medications, cancer status etc) People can first develop lymphedema several years after their original cancer treatment.
- 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.

Lymphoedema

Treatment or referral (continued)

- All patients with lymphoedema should receive a coordinated package of care and information appropriate to their needs. They should provide a 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.
- The patient's initial management may also include compression hosiery, simple lymphatic drainage and multilayered lymphoedema bandaging (MLLB) and/or Manual Lymphatic Drainage (MLD).
- Ongoing intensive therapy for complex patients may involve skin care, exercise/movement, elevation, MLD, MLLB, Intensive therapy will be provided by a practitioner trained at specialist level.
- 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 and self monitoring.
- 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.
- Refer to MDT members as appropriate for additional supportive care needs.
- Telephone follow up may be suitable for stable patients ie post CDT (Complex Decongestive Therapy) or to check fit of compression garment.
- Patients who are not responding to lymphedema management, as per the therapist's clinical reasoning and judgement, should be referred to a lymphedema specialist clinic for advice. This should include specialist assessment by vascular, dermatology, oncology and palliative care medical staff for further assessment and investigations regarding the more complex presentation.
- 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 SLD depending on complexity, compression bandaging, compression garments, individualised foam pads and self monitioring.

Lymphoedema

Treatment or referral (continued)

- If genital oedema is present, reiterate skin care, hygiene measures and prompt reporting of cellulitis.
- 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.
- Promote access to any local support groups.
- Research is currently evaluating the role of laser therapy for fibrosis management and intermittent pneumatic compression (IPC) as an adjunct to CDT. There is no national agreement to date on the use of these modalities, and further research is recommended.
- 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 eg vascular damage.
- Factors indicating successful treatment intervention will include:
  - reduction in limb volume
  - reduction in limb circumference
  - improvement in skin texture and condition
  - psychological improvement
  - reduced episodes of cellulitis
  - improved dexterity
  - reduction in pain
- Changes are usually evident in the first two weeks of treatment, however for the more chronic presentations this may take up to six weeks.

Monitoring/review

Intervention for patients without lymphoedema but considered to be at risk ie 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.

- 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.
- Some people may be appropriate for prophylactic compression garments despite no swelling but these must be fitted and 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 for both the garments and the staff to do an appropriate assessment to fit the correct sleeve or stocking.
- Advice re Body Mass Index and provide dietetic advice if required.
- Help patient return to normal use and active lifestyle.
- Provide advice and support about issues related to body image and sexual function. Refer on as necessary.
- Manage scar tissue and mobilisation post op.
- 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.
- Patients with lymphoedema: provide treatment plan, CDT, regular follow up, cycle of treatment and life long maintenance. Patients may require CDT repeatedly if they experience secondary complications such as recurrent cellulitis.
- 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 and reiterate cellulitis advice.
- Ensure patient is aware of any local/national support groups.
- Discharge for stable patients to care of GP but with self re-referral back if secondary complication or if significant change in swelling volume.
- Assess psychological impact of lymphoedema and refer as appropriate.

Lymphoedema

Monitoring/review (continued)

- Monitor for psychological distress related to body image and sexual issues, pain, weight/BMI and request referral as appropriate.

Palliative care

- Introduce adapted treatment plan (CDT etc) and establish realistic goals. Cellulitis is a risk factor at this stage.
- Monitor for lymphorrhea and treat urgently.
- Patients with existing lymphoedema: adapted treatment plan/CDT.
- Refer to additional members of MDT as appropriate.
- Aim to prevent risk and secondary complications: cellulitis, lymphorrhea, swelling extending to adjacent area of body, heavy arm which may affect balance.
- Patients with fungating wounds and oedematous arm/trunk should be referred to lymphedema specialist and/or Tissue Viability Nurse Specialist.
- Prompt recognition of deep vein thrombosis and investigation.

Assessment

- Seek advice from metastatic spinal cord compression (MSCC) network coordinator and if appropriate refer on to specialist for further investigations/assessment (see NICE Clinical Guidelines Metastatic Spinal Cord Compression 2008). https://www.nice.org.uk/Guidance/CG75
- Assume spinal cord compression and spine unstable until investigations prove otherwise.
- Access specialist therapist advice as appropriate.
- Advise flat bed rest with neutral spine alignment.
- Provide patient/carer with information and reassurance.
- Ensure transfer to local imaging centre lying flat (as pain allows).
- Assume spine 'unstable' until MDT decision made regarding spinal stability.
- For cervical lesions, ensure immobilisation with hard collar and instruct patient, carers and nursing staff regarding fitting of collar, care and maintenance.
- Refer to physiotherapist within 24 hours of admission, occupational therapist within 24/48 hours of admission and to member of MDT as appropriate: social worker, specialist nurse, specialist palliative care team, clinical psychologist, dietitian, speech and language therapist, hospital chaplain etc.
- Ensure flat bed rest with neutral spine alignment.
- Provide information and reassurance to patient/carers.
- Carry out holistic assessment.
- Undertake assessment for co-morbidities.
- Introduce self and explain role of physiotherapist/ occupational therapist.
- Carry out subjective assessment.
- Undertake respiratory assessment and treat as appropriate.
- Carry out neurological assessment.
- Teach active, active/assisted exercises; perform passive movements within pain limits as appropriate.
- Refer to specialist physiotherapist and occupational therapist for advice or further management as appropriate.
- Ensure good positioning.
- Provide advise on pressure relief management.

Identification of risk

- Reinforce patient information for people at risk of bone metastases ie breast, prostate and lung cancer.
- Undertake red flag assessment for people with and without a cancer diagnosis. Awareness of high risk cancers: breast, prostate and lung. Patients with cancer who describe one or more of the following need urgent assessment on the basis of their signs and symptoms:
- Pain is usually the first presenting symptom and has often been present for a number of weeks before MSCC is diagnosed.
- Pain may be new, or may present as a significant change in the character of longstanding pain. It is often described as unremitting, and is associated with feelings of anguish and despair. These may be classed as early presentation triggers.
- Pain is usually in the back but can be radicular, often described as a tight band around the chest or abdomen.
- Later presenting symptoms are motor deficits (eg muscle weakness, loss of coordination, paralysis), sensory deficits (eg paraesthesia, loss of sensation) or autonomic dysfunction (bladder or bowel problems).
- (NB 1:4 patients with MSCC do not have a diagnosed primary cancer)

Treatment and referral

NB. A clinical discussion about the need for bracing needs to take place prior to mobilisation. A decision about spinal stability has to be made by MDT and documented in the medical record. Once this has been done and the brace fitted by an orthotist (if indicated) then the spine should be treated as stable.

- Agree stability of spine with MDT, ideally including surgeon, radiologist, oncologist and physiotherapist. Document in notes.
- Monitor and gather information.

Surgery

- Ensure flat bed rest and spinal alignment during transfer to specialist neuro-surgical centre.
- For cervical lesions, ensure immobilisation with hard collar. Instructions to patient, carers and nursing staff regarding fitting of collar, care and maintenance.
- Liaise with specialist neuro-surgical physiotherapist.
- Maintain respiratory function.
- Teach active, active/assisted exercises, perform passive movements within strict pain limits as appropriate and ensure good positioning at all times.
- Continue to provide patient/carer with information and reassurance.

Radiotherapy (if surgery not appropriate).

- Ensure flat bed rest and spinal alignment during transfer.
- For cervical lesions, ensure immobilisation with hard collar. Provide instructions to patient, carers and nursing staff regarding fitting of the collar, routine care and maintenance. Spinal bracing to be provided as appropriate if thoracic or lumbar lesion.
- Maintain respiratory function.
- Teach active, active/assisted exercises, perform passive movements within strict pain limits as appropriate and ensure good positioning at all times.
- Continue to provide patient/carer with information and reassurance.

- Stabilise spine as agreed by MDT, ideally including surgeon, radiologist, oncologist and physiotherapist then document in medical record.
- Provide information and reassurance to patient and carers.
- Assess emotional and psychological state.
- Carry out neurological assessment.
- Maintain respiratory function.

Metastatic spinal cord compression

Treatment or referral (continued)

- Teach active, active/assisted exercises, perform passive movements within pain limits as appropriate and ensure good positioning at all times.
- Commence gentle mobilisation as soon as possible and when pain well controlled.
- Encourage gradual sitting from supine to 45 degrees initially. If tolerated progress to 60 and 90 degrees as able, usually the same day. Monitor neurology and pain during this process.
- Carry out manual handling risk assessment for pressure relief, mobility and transfers.
- Undertake assessment of balance and sitting over edge of bed with or without support from therapist depending on level of spinal cord compression.
- Carry out mobility assessment and gradually mobilise as patient's condition allows and as per agreed local protocol (NB. Return to bedrest on increased symptoms such as increased pain and/or neurological symptoms).
- Teach transfers as appropriate.
- Complete assessment for mobility aids and gait reeducation, stairs assessment and continue rehabilitation.
- If patient has no sitting balance, transfer using hoist and continue rehabilitation as appropriate.
- Refer to MDT member as appropriate: social worker, specialist nurse, specialist palliative care team, clinical psychologist or counsellor, dietician, SALT, hospital chaplain etc.
- If pain limits patient's mobility, consider the use of a brace. Refer to orthotist for assessment.
- Carry out wheelchair assessment, pressure relieving cushion and provide advice on regular pressure relief.
- Maximise functional potential and assist patients with activities to minimise physical dysfunction.
- Provide advice and education on anxiety management/relaxation techniques.
- Assist with psychological adjustment and goal setting.
- related to loss of functional independence, self esteem and quality of life.
- Carry out transfers assessment – bed/chair/toilet/car/bath.
- Suggest prescription of activities of daily living equipment and ordering.
- Teach carers/family on use of complex equipment (hoist/wheelchair/other aids).

Metastatic spinal cord compression

Treatment or referral (continued)

- Complete seating and positioning assessment including wheelchair and pressure cushion prescription as indicated.
- Assess functional roles including primary care/ leisure/work/family/social.
- Assess home environment.
- Recognise when end of life approaching, explore needs and adjust interventions accordingly.
- Inform relevant MDT members.
- Refer to local end of life policy.
- Identify if preferred place of care has been addressed and decided on. Review if needed and help to facilitate preferred place of care.
- Provide carer support.
- Arrange collection of equipment as appropriate.
- Advise on positioning and pressure management.

The majority of these interventions will be carried out by physiotherapists and occupational therapists.

Monitoring/review

- Prepare patient and carers for discharge.
- Work closely with MDT to facilitate discharge.
- Ensure procedures completed for equipment delivery/installation, transport and care arrangements.
- Refer to specialist services for continued rehab/ support as appropriate (NB. Consider local referral criteria and engage MDT in decision making re: rehabilitation potential.
- Provide carer with education on moving and handling and use of equipment.
- Help patient optimise functional potential; set and review realistic rehabilitation goals for improving mobility and quality of life and continued involvement in valued activities (work, leisure, social).
- Facilitate adjustment to loss and disability
- Recognise and respond to highly complex physical, emotional and psychological needs and refer for specialist support as necessary.
- Facilitate patient remaining at home where appropriate.
- Provide carer education on moving and handling and use of equipment.
- Facilitate adjustment to loss and functional impairment/disability.
- Undertake environmental assessment and reassessment and adaptation as appropriate – equipment prescription/ordering as indicated.

Assessment

- Assess respiratory status especially in people with preexisting respiratory disease if being referred for surgery.
- Commence chest physiotherapy to suit individual requirements.
- Help patient achieve physical and respiratory fitness prior to surgery.
- Assess nutritional requirements, status and any mobility factors which affect nutritional intake.
- Complete an initial assessment of patient's functional, social, emotional, spiritual and psychological needs including details of home environment.
- Order and fit appropriate equipment to help improve mobility.
- Complete review of patient's occupational history in order to establish which activities are significant to the patient and why.
- Establish with patient and carers their expectations and goals

Mobility

Treatment and referral

- Ensure patient requiring surgery is referred on day of admission.
- Complete an initial assessment of patient's functional, social, emotional, spiritual and psychological needs including details of home environment for example, stairs, toileting.
- Assess respiratory status, mobility and general physical fitness.
- Teach patient exercises for maintaining circulation and general muscle tone.
- See patient within first day of operation and subsequently as required.
- Provide chest physiotherapy to achieve optimal respiratory status and aid clearance of secretions.
- Teach patient exercises for maintenance of circulation and general muscle tone.
- Assess and treat mobility and functional movement problems.
- Assess ability to transfer out of bed to chair and mobilise.
- Progress mobility as able.
- Provide information on post-op treatment.
- Advise patient about effective exercise, lifting and general activity, with written support materials.
- Ensure any equipment required is provided prior to discharge.
- Arrange outpatient community based rehabilitation if required.
- Establish treatment plan and goals with patient and carers to enable patient to reach and maintain optimum level of independence.
- Provide treatment as indicated, monitoring and reviewing effectiveness of activity or intervention, revising it as necessary.
- Enable patient to engage in social, leisure pursuits and interests.
- Conduct home assessment/access visit if indicated and implement recommendations.
- Facilitate safe discharge by liaison with patient, MDT, carers and community support services.
- Provide ongoing monitoring and support to maintain patient's independence in all activities of daily living.
- Advise carers on safe handling and moving techniques for use in the home environment, if necessary.

Mobility

Treatment or referral (continued)

- Assess functional ability and equipment required to enable maximum functioning in home environment
- Discharge patient when recommendations implemented and goals achieved.
- Assess whether any mobility factors are affecting nutritional intake.
- If functional capacity is still an issue, assess mobility and general physical condition.
- Assess for specific musculo-skeletal problems.
- Advise on lifting and general exercise and activity.
- Assess whether pelvic floor function and urinary/faecal incontinence are part of the problem. (Refer to continence pathway).
- Establish treatment plans and goals with patient and carers to enable patient to reach and maintain optimum level of independence.
- Provide treatment as indicated including opportunities for patient's to engage in activities of daily living including personal, social and domestic activities.
- Conduct home assessment if indicated and implement recommendations.
- Provide ongoing monitoring and support to maintain patient's independence in all activities of daily living.
- Provide advice on energy conservation and techniques in activities of daily living. (Refer to fatigue pathway).
- Advise carers on safe handling and moving techniques for use in the home environment, if necessary.
- Complete moving and handling risk assessment and relevant documentation.
- Ensure equipment required to facilitate independence in activities of daily living and/or care is arranged in timely manner.
- Discharge patient when recommendations implemented and goals achieved.
- Advise patients on coping strategies.
- Assess for and provide resting or dynamic orthoses as indicated.

Monitoring/review

- Assess physical fitness in clinic and include in out patient exercise programme – every six months.
- Progress mobility as able.
- Patients should receive advice on increasing levels of physical activity and what the benefits are.
- Arrange outpatient or community rehabilitation if required.
- Patient given contact name and telephone number of physiotherapist to contact between discharge and outpatient appointment in case of problems with mobility and function.
- Review patient's occupational history in order to establish significance to patient's needs and identify their priorities.
- Assist patient in adapting activities of daily living in order to allow continued participation.
- Advise on services and equipment to support effective functioning in activities of daily living.
- Provide advice and information on accessing/ maintaining social and leisure pursuits including benefits advice officer, blue badge scheme, shop mobility schemes.
- Discharge patient when recommendations implemented and goals achieved.
- Adapt nutritional plans depending on treatment, treatment effects and impact on mobility.

Palliative care

- Make immediate assessment with appropriate level of support and rehabilitation as indicated by patient's requirements.
- Refer to palliative care team for physical rehabilitation if indicated.
- Assess functional ability and equipment required to enable maximum functioning in home environment.
- Conduct home assessment if indicated and implement recommendations.
- Ensure equipment required to facilitate independence in activities of daily living and/or care is arranged without undue delay.
- Assess for and arrange provision of wheelchair and appropriate pressure relief cushion where indicated.
- Provide precautionary and preventative information about protecting vulnerable bones if patient has metastatic bone involvement.
- Assess and provide static or dynamic orthoses as indicated.
- Advise and educate carers on safe manual handling and moving techniques for use in the home environment, if necessary.

Mobility

Monitoring/review (continued)

- Provide ongoing monitoring and support in order to achieve patient's goals.
- Ensure equipment required to facilitate independence in activities of daily living and/or care is made available within one working day of request.
- To assess for and provide resting or dynamic orthoses as indicated.
- Assess for and provide wheelchair and equipment to promote comfort and control.

Interventions in the poor mobility and loss of function pathway will be mostly carried out by physiotherapists and occupational therapists.

Pain

Assessment

- Undertake holistic/biopsychosocial assessment.
- Be guided by the nature and cause of the pain and the context in which it is present ie intractable pain in a palliative patient differs from chronic pain in a cancer survivor.
- Consider the following three components in all patients:
  - a description of the pain
  - responses to the pain eg emotional, physical, functional, pain behaviours etc
  - the impact of pain on the person's life
- Consider context of the pain. Is it worse on movement, when patient is anxious etc.
- Consider presence of other symptoms eg fatigue, breathlessness, cachexia, psychological distress.
- Consider physical impairments and functional limitations (Jones and Rivett, 2004) to help guide clinical reasoning.
- Consider the use of outcome measures for pain severity such as numerical rating scale (NRS), visual analogue scale (VAS); pain severity and interference (BPI); pain quality (McGill Pain Questionnaire) (Melzack 1975).
- Consider physical fitness, quality of life.
- Set patient determined goals.
- Consider referral to other services eg clinical psychology, dietetics, chaplaincy, social work.

Palliative care/end of life

- Continually assess enabling AHP to respond in a timely manner to patients needs.

The majority of the pain care pathway will be undertaken by physiotherapist and occupational therapist's.

Screening

- Screening for onward referral should be an integral part of pain assessment.
- Pain assessment to be undertake by any trained member of the MDT.

Identification of risk

- History of prolonged pain problems.
- High levels of acute post-operative pain.
- High levels of anxiety.
- Depression.
- Multiple interventions eg repeated surgery, surgery + radiotherapy +/- chemotherapy.
- Identify cause(s) of pain ie pain due to cancer or due to cancer treatments or a combination.
- Consider use of Brief Pain Inventory (BPI) to assess severity of pain and interference to life (Cleeland and Ryan 1994). NB on numerical rating scales Mild (0-4) Moderate (5–6) Severe (7–10) (Serlin et al. 1995).

Treatment and referral

- Refer to Physiotherapy or Occupational therapy if pain results in any of the following (NB this is not an exhaustive list):
  - loss of general mobility
  - difficulty performing activities of daily living/low levels of performance status
  - maladaptive pain behaviours eg fear, avoidance
  - muscle weakness
  - joint stiffness
  - loss of social/family/productivity (including paid work) role
  - distress due to any of the above
- Refer to dietitian if pain results in poor nutritional status

Principles

- Undertake holistic assessment using biopsychosocial model.
- Incorporate identification of the impact of beliefs, thoughts and emotional responses towards the pain experience on patient and carer.
- Incorporate identification of pain impact on functional performance: self-care, leisure, productivity and maintenance of roles.
- Set SMART goals.

Physiotherapist

- Teach therapeutic exercise.
- Set graded and purposeful activity.
- Provide postural re-education.
- Massage and mobilise soft-tissue.
- Provide Transcutaneous Electrical Nerve Stimulation (TENS).
- Use heat and cold to help ease pain.
- Help with positioning.
- Provide use of orthoses.
- Offer complementary and alternative medicine (if appropriately trained) eg acupuncture, mindfulness based stress reduction.
- Suggest cognitive-behavioural approaches (if appropriately trained).

Occupational Therapist

- Ensure graded engagement in meaningful activity using goal setting and activity scheduling techniques.
- Manage anxiety.
- Help with relaxation and provide guided imagery training.
- Consider sleep hygiene.

Pain

Treatment or referral (continued)

- Identify distraction activities.
- Help with lifestyle adjustment; to include task adaptation, work simplification, compensatory techniques, time management, ergonomic principles and energy conservation.
- Provide equipment and adaptations.
- Advise on posture, seating, positioning and pressure care.
- Suggest cognitive-behavioural approaches (if appropriately trained).

Education

- Consider patient, carer and family information wherever possible to complement interventions.
- Provide patient-held goal setting record.
- Signpost to other services eg psychology cancer help centres if necessary.

Monitoring/review

- Ensure review and monitoring is individualised and decided by continual assessment.
- Review at key stages in patient pathway.
- Recognise the issues of living with pain.
- Support the patient through the continual renegotiations of their identity, and the substantial adjustments required to living with and managing cancer pain.

Being told ‘you have cancer’ can affect so much more than your health – it can also affect your family, your job, even your ability to pay the bills. But you’re still you. We get that. And, after over 100 years of helping people through cancer, we get what’s most important: that you’re treated as a person, not just a patient.

It’s why we’ll take the time to understand you and all that matters to you, so we can help you get the support you need to take care of your health, protect your personal relationships and deal with money and work worries.

We’re here to help you find your best way through from the moment of diagnosis, so you’re able to live life as fully as you can. **For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk**

Macmillan.org.uk