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National Cancer Action Team

Rehabilitation Care Pathway

Anorexia/Cachexia/ Weight Loss

Assessment

Intervention

- 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 & proposed form of treatment
- Present patient at MDT
- Liaise with previous AHPs/ social colleagues involved
- Undertake detailed dietary assessment to include anthropometric & biochemical measurements
- Influence organisational approach to provision of food
- Establish case history, current extent of disease & proposed form of treatment
- Liaise with previous AHPs/ social colleagues involved
- Assess for body image alteration/ adjustment
- Screen for sexual function problems & refer on as necessary
- Establish soft tissue patency needs
- Assess functional ability relating to activity stamina, food preparation & eating

Treatment

Intervention

- Recognise signs of anxiety/ depression & provide anxiety management as appropriate
- Agree realistic goals with patient & carers to include quality of life
- Identify nutritionally related symptoms resulting in weight loss/anorexia/cachexia
- Offer dietetic advice for management of these symptoms – see below
- Offer dietetic advice for management of taste changes
- Offer dietetic advice for management of dry mouth
- Offer dietetic advice for management of oral problems
- Offer dietetic advice for management of nausea
- Offer dietetic advice for management of vomiting
- Offer dietetic advice for management of diarrhoea
- Offer dietetic advice for management of constipation
- Offer dietetic advice for management of malabsorption
- Offer dietetic advice for management of weakness
- Offer dietetic advice for management of loss of appetite
- Offer dietetic advice for management of early satiety

- Offer dietetic advice for management of weight loss
- Offer dietetic advice for management of GI disturbances
- Offer dietetic advice for management of bowel obstruction
- Offer dietetic advice for management of reflux
- Consider/manage oral nutritional supplements both non prescribable & 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 & carers about access & referral to other appropriate agencies
- Influence organisational approach to provision of food
- Provide exercise advice & treatment to maintain muscle bulk, improve stamina & functional ability
- Advise on exercise regime & activity tolerance
- Consider body image adjustment & psychological concerns
- Consider relaxation
- Consider visualisation
- Consider distraction therapy
- Assess & address issues around meals, timings & preparation, weakness & pressure care & equipment provision
- Provide food preparation help – from shopping to cooking
- Refer to other services/agencies as appropriate
- Provide support with clothing

Monitoring/Survivorship

Intervention

- Undertake reassessment at each key point in pathway
- Review planned interventions at each key point in pathway
- Provide ongoing communication with MDT & other services/agencies
- Consider timeliness of interventions
- Discharge as appropriate
- Refer to community Dietitian for ongoing monitoring & 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 & address issues around meals, timings & preparation, weakness & pressure care & equipment provision

Palliative Care/ End of Life Care

Intervention

- Consider body image adjustment
- Assess & address issues around meals, timings & preparation, weakness & pressure care & equipment provision
- Consider appropriateness of interventions
- Discuss realistic goals with patient & 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

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National Cancer Action Team

Rehabilitation Care Pathway

Breathlessness

Presentation

Triage

- Identify reversible causes
- Assess breathlessness severity using validated tool such as BORG (Gunner Borg) to determine outcome scale which measures rate of perceived exertion
- Refer on to Breathlessness team, key worker & other AHP's

Specialist Rehabilitation Assessment

- Assess knowledge of patient & 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 e.g. 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 & need for home oxygen
- Assess use of respiratory medication such as inhalers & nebulisers
- Assess & score activities of daily living & patient's current problems
- Assess anxiety
- Screen nutrition status
- Assess nutritional status, intake & agree interventions & care plan
- Liaise with MDT members & refer on as necessary

Treatment/Intervention

Knowledge

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 & diaphragmatic breathing

- Advise on pacing, prioritising & planning
- Referral to Wheelchair Services for wheelchair assessment & provision
- Education of patient & carers
- Provision of patient information
- General advice & support
- Setting SMART goals - specific, measurable, accurate, realistic & timely
- Exercise prescription
- Need for mobility aids
- Respiratory mucociliary chest clearance techniques
- Increase air flow – e.g. 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 nebulised therapy if appropriate
- Provide advice on or request other pharmacological interventions (e.g. opioids)
- Equipment provision
- Home visits
- Anxiety management techniques
- Minor & major home adaptations
- Role retraining
- Assess functional ability to feed
- Assess nutrition status, intake, intervention, care plan
- Commence nutrition support including oral supplements & food fortification
- Liaise with MDT members

Review/Monitoring

Intervention

- 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 & planning
  - Wheelchair assessment & provision
  - Education of patient & carers
  - Provide patient information
  - General advice & support
  - Individual goal setting
  - Agree case management
  - Nutritional status

- Consider patient self-management & provision of contact details for re-accessing rehab services
- Patient choice regarding telephone or face-to-face review & agree follow up options
- Refer appropriately on to other services
- Determine frequency of:
  - Ongoing monitoring
  - Communicate plan & outcome interventions with MDT & 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 & Language Therapist and Dietitians.

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National Cancer Action Team

Rehabilitation Care Pathway

Communication Difficulties

At Risk

Intervention

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

Diagnosis & Care Planning

Presentation

Intervention

- Establish need for interpreter
- Liaise with previous AHP's, social services & PCT colleagues & provide AHP differential diagnosis
- Establish case history, current extent of disease & proposed form of treatment
- Carry out initial assessment including: -
  - oro-facial/laryngeal motor evaluation
  - assessment of receptive – auditory & visual
  - assessment of receptive language-auditory & reading
  - assessment of expressive language – verbal & written
  - assessment of speech production including fluency
- SALT 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 SALT diagnosis and/ or summary of findings to patient, communication partner & healthcare professionals
- Advise medical staff on proposed treatment plan

Treatment

Intervention

- Educate patient, communication partners, appropriate health and social care professionals on patient specific communication difficulties
- Refer onto other agencies & professionals as appropriate
- Consider co-morbidities & 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 & 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 & social professionals
- Continue education, support & advocacy throughout the pathway
- Provide specialist support for professional colleagues

Monitoring

Intervention

- Review goals & interventions in the light of changing circumstances
- Review effectiveness of treatment
- Continually re-assess patient & their communication skills & treat accordingly in response to changes in presentation, medical treatment, disease progression & response to medication

- Alert MDT or consultant to any change in patient presentation including improvement or deterioration
- Review & monitor patient & 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

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National Cancer Action Team

Rehabilitation Care Pathway

Continence

Knowledge

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 & neural)
- Intact spinal pathways (brain S2 S3)
- Intact physiological urinary & bowel systems
- Mobility to get to a toilet, dexterity to undress

Identification

Intervention

- 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

Screen for Referral

Intervention

- 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

Referral

Intervention

- 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

Specialist assessment

Intervention

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 & 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 & exercise levels & evidence of decreased activity & physical fitness
  - Pain
  - Current disease status & treatment. Identification other constraints such as bone metastases, neutropenia etc
  - Medication
  - Relationships
  - Patient perspective
  - Mood e.g. depression
  - Other relevant symptoms
  - Cognition & 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 e.g. depression
  - Other relevant symptoms
  - Cognition & perception
  - Other comorbidities

Specialist Intervention

Intervention

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 UTI prevention/bladder irritation
- Consider use of acupuncture to help bladder irritation

Education/Information for Patients/Carers

Intervention

- Provide access to relevant & timely information. Discuss & reinforce this with patient and carer as appropriate
- Provide written information including continence strategies (may need different language & formats)
- Provide information on impact of disease & treatment

- Direct & 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

Patient/Carer Support

Intervention

- 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

Ongoing Review/Goal Setting/Monitoring & Survivorship

Intervention

- 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 &/ or toilet facilities where this is appropriate to help self-management strategies

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National Cancer Action Team

Rehabilitation Care Pathway

Dysphagia

Assessment

Intervention

- Carry out nutritional screening for malnutrition
- Review any existing screening & undertake assessments
- Communicate with MDT for management plan
- Establish case history, current extent of disease & proposed form of treatment
- Present patient at MDT. Discuss ethical issues/quality of life & potential feeding routes
- Liaise with professional colleagues
- Carry out detailed dietary assessment including assessment of current intake, nutritional status, functional capacity, biochemical markers & 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 & 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 & 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 & MDT on diagnostic findings & recommendations for treatment
- Inform patient of treatment planning process - discussion with patient & MDT on effects of cancer & planned treatment on eating & drinking, feeding options/ risk management & quality of life issues
- Inform on treatment planning process - information to patient/carers & MDT re likely impact of treatment & disease on swallow function

Treatment

Intervention

- Agree realistic goals with patient & carers to include quality of life
- Consider & manage texture, energy & modification of diet
- Consider & manage oral nutritional supplements both non prescribable & prescribable

- Consider & manage prophylactic nutritional support
- Consider & manage enteral & parenteral nutritional support
- Consider & manage dietary management of co-morbidities
- Refer to other services & agencies as appropriate
- Assess impact of interventions on quality of life
- Give written information for patient & carers
- Manage, in liaison with the MDT, acute & chronic side effects of oncological treatment that impact on swallowing
- Provide support together with the MDT on tracheostomy management & weaning

Surgery

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

Radiotherapy/Chemotherapy

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

- Provide emergency on-call service (24/7)
- Assess & manage range of movement – temporo mandibular joint, head, shoulder & neck
- Assess cause & severity & treat as appropriate
- Provide breathing control oxygen therapy (needs to be prescribed by Doctor)
- Offer advice on positioning & posture

Monitoring/Survivorship

Intervention

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

Palliative Care/End of Life Care

Intervention

- Consider appropriateness of interventions
- Discuss realistic goals with patient & carers including quality of life issues
- Discuss with MDT & Palliative Care Team

- Withdraw nutritional supplements & artificial feeding if appropriate
- Support patients & carers to facilitate withdrawal of nutritional support
- Consider quality of life & 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 & ethical issues related to interventions & eating & drinking functions
- Monitor swallowing function & recommend management strategies to support continued oral nutrition
- Discuss realistic goals with patient & carers including quality of life & 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

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National Cancer Action Team

Rehabilitation Care Pathway

Fatigue/Energy Management

Identification

- 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

Screen for Referral

Intervention

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

Referral

Intervention

- 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

Specialist assessment

Intervention

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

- Other relevant symptoms
- Other comorbidities
- Refer on as appropriate

Specialist Intervention

Intervention

Consider

- Agree realistic goals with patient
- Relaxation & sleep techniques
- Energy conservation, pacing & compensatory techniques
- Anxiety & 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 & complementary therapies
- Sleep hygiene
- Cognitive support
- Medical assessment & re-assessment
- Consider group or individual setting
- Consider vocational rehabilitation

Education/Information for Patients/Carers

Intervention

Provide access to relevant & timely information

- Reinforce information about fatigue
- Provide written information including exercise programme for home use (language & format)
- Provide information on impact of disease & treatment

Patient/Carer Support

Intervention

- Identify carer needs
- Refer on as appropriate
- Signpost to support groups
- Enable/empower
- Consider respite or continuing care

Ongoing Review/Goal Setting/Monitoring & Survivorship

Intervention

Consider

- Appropriately reassess & refer on multidisciplinary working including reassessment of exercises & 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

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National Cancer Action Team

Rehabilitation Care Pathway

Lymphoedema

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

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

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

Factors indicating successful treatment intervention will include:

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

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

At risk patients should be:

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

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

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

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

Diagnosis & Care Planning

Intervention

D1

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

D2

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

Treatment

Intervention

T1

- Provide information prescription and identify keyworker

T2

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

T3

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

T4

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

T5

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

T6

- **Chemotherapy** - provide advice on prevention to protect against damage to at risk limb & warn of potential of oedema as direct side effect of treatment

T7

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

T8

- At risk treatment areas - If patient has had radiotherapy to the following areas, their risk of lymphoedema is higher:
  - 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

T9

- Advise on recommended exercises, positioning and skincare measures

Post Treatment

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

PT1

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

PT2

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

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

PT3

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

PT4

- Help patient return to normal use & active lifestyle.

PT5

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

PT6

- Manage scar tissue and mobilisation post op

PT7

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

Interventions for patients **with** lymphoedema

PT8

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

PT9

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

PT10

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

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

PT11

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

PT12

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

PT13

- If the patient has any midline lymphoedema, this will need managing by a Lymphoedema Specialist and is likely to include daily skin care, exercise, MLD and/or simple lymphatic drainage (SLD) (depending on complexity) , compression bandaging, compression garments, individualised foam pads & self monitoring

PT14

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

PT15

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

PT16

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

PT17

- Patients who are not responding to lymphoedema management, as per the therapist's clinical reasoning and judgement, should be referred to a lymphoedema specialist clinic for advice. This should include specialist assessment by vascular, dermatology, oncology &

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

PT18

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

PT19

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

PT20

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

PT21

- Promote access to any local support groups

PT22

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

Monitoring/ Survivorship

M1

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

M2

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

M3

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

M4

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

M5

- Assess psychological impact of lymphoedema & refer as appropriate

M6

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

Palliative Care

Intervention

P1

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

P2

- Monitor for lymphorrhea & treat urgently

P3

- Patients with existing lymphoedema: adapted treatment plan/CDT

P4

- Refer to additional members of MDT as appropriate

P5

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

P6

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

P7

- Prompt recognition of DVT and investigation

End of Life Care

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

E1

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

E2

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

E3

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

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

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Rehabilitation Care Pathway

Metastatic Spinal Cord Compression

Presentation of confirmed Spinal Cord Compression (on admission)

Intervention

- Assume spine 'unstable' until MDT decision made regarding spinal stability
- For cervical lesions, ensure immobilisation with hard collar & instruct patient, carers & nursing staff regarding fitting of collar, care & maintenance
- Refer to physiotherapist within 24 hours of admission, occupational therapist within 24/ 48 hours of admission & to member of MDT as appropriate: social worker, specialist nurse, specialist palliative care team, clinical psychologist, dietitian, SALT, hospital chaplain etc
- Ensure flat bed rest with neutral spine alignment
- Provide information & reassurance to patient/ carers
- Carry out holistic assessment
- Undertake assessment for co-morbidities
- Introduce self & explain role of physiotherapist/ occupational therapist
- Carry out subjective assessment
- Undertake respiratory assessment & treat as appropriate
- Carry out neurological assessment
- Teach active, active/ assisted exercises; perform passive movements within pain limits as appropriate
- Refer to specialist physiotherapist & occupational therapist for advice or further management as appropriate
- Ensure good positioning
- Provide advise on pressure relief management

Unstable Spine – prior to treatment (surgery and/or radiotherapy)

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 & documented in the medical record. Once this has been done & the brace fitted by an orthotist (if indicated) then the spine should be treated as stable

Intervention

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

Post Hospital Discharge

Intervention

- Provide carer with education on moving & handling & use of equipment
- Help patient optimise functional potential; set & review realistic rehabilitation goals for improving mobility & quality of life & continued involvement in valued activities (work, leisure, social)
- Facilitate adjustment to loss & disability
- Recognise & respond to highly complex physical, emotional & psychological needs & refer for specialist support as necessary
- Facilitate patient remaining at home where appropriate
- Provide carer education on moving & handling & use of equipment
- Facilitate adjustment to loss & functional impairment/ disability
- Undertake environmental assessment & reassessment & adaptation as appropriate – equipment prescription/ ordering as indicated
- Provide access to other professionals including social worker, SLT & Dietitian

Approaching End of Life

Intervention

- Recognise when end of life approaching, explore needs & adjust interventions accordingly
- Inform relevant MDT members
- Refer to local end of life policy
- Identify if preferred place of care has been addressed & decided on. Review if needed & help to facilitate preferred place of care
- Provide carer support
- Arrange collection of equipment as appropriate
- Advise on positioning & pressure management

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

At Risk

Intervention

- Reinforce patient information for people at risk of bone metastases i.e. breast, prostate & lung cancer

Undertake red flag assessment for people with & without a cancer diagnosis. Awareness of high risk cancers: breast, prostate & lung. Patients with cancer who describe one or more of the following need urgent assessment on the basis of their signs & 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 (e.g. muscle weakness, loss of coordination, paralysis), sensory deficits (e.g. paraesthesia, loss of sensation) or autonomic dysfunction (bladder or bowel problems).

(NB 1:4 patients with MSCC do not have a diagnosed primary cancer)

Presentation of suspected spinal cord compression (no specified location)

Intervention

- Seek advice from MSCC network coordinator & if appropriate refer on to specialist for further investigations / assessment (see NICE Clinical Guidelines Metastatic Spinal Cord Compression 2008)
- Assume spinal cord compression & 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 & reassurance
- Ensure transfer to local imaging centre lying flat (as pain allows)

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 & ensure good positioning at all times
- Continue to provide patient/carer with information & reassurance

Radiotherapy (if surgery not appropriate)

- Ensure flat bed rest & 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 & ensure good positioning at all times
- Continue to provide patient/ carer with information & reassurance

Stable spine – after treatment (surgery and/ or radiotherapy)

Intervention

- Stabilise spine as agreed by MDT, ideally including surgeon, radiologist, oncologist & physiotherapist then document in medical record
- Provide information & reassurance to patient & carers
- Assess emotional & psychological state
- Carry out neurological assessment
- Maintain respiratory function
- Teach active, active/ assisted exercises, perform passive movements within pain limits as appropriate & ensure good positioning at all times
- Commence gentle mobilisation as soon as possible & when pain well controlled
- Encourage gradual sitting from supine to 45 degrees initially. If tolerated progress to 60 & 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 & sitting over edge of bed with or without support from therapist depending on level of spinal cord compression
- Carry out mobility assessment & gradually mobilise as patient's condition allows & 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 & gait re-education, stairs assessment & 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 & provide advice on regular pressure relief
- Maximise functional potential and assist patients with activities to minimise physical dysfunction
- Provide advice & education on anxiety management/ relaxation techniques
- Assist with psychological adjustment & goal setting related to loss of functional independence, self esteem & quality of life
- Carry out transfers assessment – bed/ chair/ toilet/ car/ bath
- Suggest prescription of activities of daily living equipment & ordering
- Teach carers/ family on use of complex equipment (hoist/ wheelchair/ other aids)
- Complete seating & positioning assessment including wheelchair & pressure cushion prescription as indicated
- Assess functional roles including primary care/ leisure/ work/ family/ social
- Assess home environment

Discharge

Intervention

- Prepare patient & carers for discharge
- Work closely with MDT to facilitate discharge
- Ensure procedures completed for equipment delivery/ installation, transport & care arrangements
- Refer to specialist services for continued rehab/ support as appropriate (NB. Consider local referral criteria & engage MDT in decision making re: rehabilitation potential

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Rehabilitation Care Pathway

Poor Mobility and Loss of Function

Diagnosis & Care Planning

Intervention

- Assess respiratory status especially in people with pre-existing respiratory disease if being referred for surgery
- Commence chest physiotherapy to suit individual requirements
- Help patient achieve physical & respiratory fitness prior to surgery
- Assess nutritional requirements, status & any mobility factors which affect nutritional intake
- Complete an initial assessment of patient's functional, social, emotional, spiritual & 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

Treatment

Intervention

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

Post Treatment

Intervention

- If functional capacity is still an issue, assess mobility & general physical condition
- Assess for specific musculo-skeletal problems
- Advise on lifting & general exercise & activity
- Assess whether pelvic floor function & urinary/ faecal incontinence are part of the problem. (Refer to continence pathway)
- Establish treatment plans & goals with patient & carers to enable patient to reach & maintain optimum level of independence
- Provide treatment as indicated including opportunities for patient's to engage in activities of daily living including personal, social & domestic activities
- Conduct home assessment if indicated & implement recommendations
- Provide ongoing monitoring & support to maintain patient's independence in all activities of daily living
- Provide advice on energy conservation & techniques in activities of daily living. (Refer to fatigue pathway)
- Advise carers on safe handling & 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 & goals achieved
- Advise patients on coping strategies
- Assess for and provide resting or dynamic orthoses as indicated

Monitoring/ Survivorship

Intervention

- Assess physical fitness in clinic & include in out patient exercise programme - every 6 months
- Progress mobility as able
- Patients should receive advice on increasing levels of physical activity & 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 & 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 & 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 & goals achieved
- Adapt nutritional plans depending on treatment, treatment effects & impact on mobility

Palliative Care

Intervention

- 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 & equipment required to enable maximum functioning in home environment
- Conduct home assessment if indicated & implement recommendations

- Ensure equipment required to facilitate independence in activities of daily living &/ 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
- To assess for and provide resting or dynamic orthoses as indicated
- Assess for & provide wheelchair & equipment to promote comfort & control

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

End of Life Care

Intervention

- Advise and educate carers on safe manual handling & moving techniques for use in the home environment, if necessary
- Provide ongoing monitoring & support in order to achieve patient's goals
- Ensure equipment required to facilitate independence in activities of daily living &/ or care is made available within 1 working day of request

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Rehabilitation Care Pathway

Pain

At risk

- History of prolonged pain problems
- High levels of acute post-operative pain
- High levels of anxiety
- Depression
- Multiple interventions e.g. repeated surgery, surgery + radiotherapy +/- chemotherapy

Identification

- Identify cause(s) of pain i.e 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). N.B. on numerical rating scales Mild (0-4) Moderate (5-6) Severe (7-10) (Serlin et al. 1995)

Screen for referral

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

Referral to Rehabilitation

- Refer to Physiotherapy or Occupational therapy if pain results in any of the following (N.B this is not an exhaustive list):
  - loss of general mobility
  - difficulty performing activities of daily living/low levels of performance status
  - maladaptive pain behaviours e.g. 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

Specialist rehabilitation assessment

- Undertake holistic/ biopsychosocial assessment
- Be guided by the nature and cause of the pain and the context in which it is present i.e. intractable pain in a palliative patient differs from chronic pain in a cancer survivor

- Consider the following 3 components in all patients:
  - a description of the pain
  - responses to the pain e.g. 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 e.g 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 e.g clinical psychology, dietetics, chaplaincy, social work

Specialist rehabilitation intervention

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) e.g. 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
- 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 & Info for Patients & Carers

- Consider patient, carer & family information wherever possible to complement interventions
- Provide patient-held goal setting record

Patient/Carer support

- Signpost to other services eg psychology cancer help centres if necessary

Ongoing review/Goal setting/Monitoring & Survivorship

- 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.

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 & Occupational Therapist's

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