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GUIDELINES AND AUDIT
IMPLEMENTATION NETWORK

Guidelines for the Rehabilitation of Patients with Metastatic Spinal Cord Compression (MSCC) Assessment and Care provision by Occupational Therapists and Physiotherapists In the Community Setting (Northern Ireland)

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www.rqia.org.uk/GAIN

Assurance, Challenge and Improvement in Health and Social Care

Executive Summary

Metastatic Spinal Cord Compression (MSCC) occurs in approximately 5% of patients with advanced cancer, and is due to metastatic spread or direct extension of malignancy causing compression of the spinal cord or cauda equina by direct pressure and/or vertebral instability or collapse, and so threatening or causing neurological disability. It can occur in almost all malignancies but myeloma, lung, prostate and breast cancers are the most common types. ⁽⁴⁾

The National Institute for Health and Care Excellence (NICE), Quality Standard 56 (2014) ⁽¹⁾ supports a management plan that commences on admission to the Acute Sector. Effective communication between primary, secondary and tertiary care settings is essential to ensure a seamless transfer between services, providing continuity of care for patients in their preferred place of care.

There is a body of evidence recommending prompt referral to Occupational Therapists and Physiotherapists, in the acute sector, once diagnosis has been confirmed, for assessment and rehabilitation. This includes facilitating discharge, and providing recommendations for on-going rehabilitation/supportive care in the community. ⁽¹⁾

To date there is a lack of guidance for community based Occupational Therapists and Physiotherapists who provide care of patients with MSCC in the community setting across Northern Ireland.

The purpose of this document is to identify the research and clinical evidence, expert opinion and professional consensus – in order to provide best available evidence based practice for Occupational Therapists and Physiotherapists in the assessment, treatment and rehabilitation of patients living with MSCC in the community sector.

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Background

Metastatic Spinal Cord Compression (MSCC) occurs when there is pathological vertebral body collapse or direct tumour growth causing compression of the spinal cord or cauda equina. Irreversible neurological damage ensues with resulting paraplegia ⁽²⁾.

Early diagnosis and treatment is essential to prevent neurological damage and optimise outcome. To achieve this, early recognition and reporting of symptoms, simple and rapid referral pathways, urgent and appropriate investigations and prompt treatment are needed. ⁽³⁾

MSCC is a major cause of morbidity and occurs in approximately 5% of all patients diagnosed with cancer. In approximately 85% of cases it results as a consequence of metastases from a primary tumour with cancers of the lung, prostate and breast accounting for around 50% of cases. Other cancers frequently associated with MSCC include lymphoma, renal, multiple myeloma, melanoma and sarcoma. ⁽⁴⁾

The spinal column is the most common site of bony metastases with the thoracic spine most frequently affected (70%), followed by the lumbosacral (20%) and cervical (10%)^(5,6,7,4) MSCC is an oncological emergency requiring urgent investigation and immediate treatment as neurological outcome is largely determined by neurological function at the time of starting treatment ⁽⁸⁾.

Purpose of the Guideline

This clinical guideline has been developed using research evidence, expert opinion and professional consensus. This provides best available evidence based practice for Occupational Therapists and Physiotherapists delivering a patient centred approach to the assessment and treatment of patients with MSCC in the community. It should be used in conjunction with other regional and local policies relating to skin care, manual handling, anti-embolism, seating and wheelchair provision.

This guideline is not prescriptive, and should take into account individual variation and needs.

Scope of the Guideline

The guideline is targeted at community based Occupational Therapists and Physiotherapists who are involved in the management of patients who have a confirmed diagnosis of Metastatic Spinal Cord Compression (MSCC), those who have been diagnosed with a primary cancer which has the risk of developing MSCC or when it recurs following treatment.

It is also expected that the guideline will be of value to those involved in clinical governance in both primary and secondary care to ensure that arrangements are in place to deliver appropriate care to this group of patients.

This document provides guidance for referral to community Occupational Therapy and Physiotherapy, assessment, supportive care and rehabilitation for patients with MSCC, under the following subsections:

1. Referral
2. Assessment
3. Supportive Care and Rehabilitation
4. End of life Considerations

Objectives of the Guideline

- 1. To ensure early and prompt referral, diagnosis and treatment of MSCC**
Significant delays in presentation, referral and diagnosis of MSCC ⁽²⁾ exist. There is a need for prompt referral, diagnosis and treatment to optimise neurological and functional outcomes, quality of life (QOL) and survival^(8,9)
- 2. To enable Community Therapists to educate patients at high risk of MSCC and/or carers on the key features and the importance of early reporting and detection, and later in the management of MSCC.**
- 3. To provide clearer guidance on spinal stability and safe mobility/ rehabilitation** - There is a lack of clear guidance and mixed expert opinion on spinal stabilisation and mobilisation ^(10, 11)
- 4. To provide community based Physiotherapists and Occupational Therapists with clear guidance on safe assessment and treatment of patients with MSCC** - Often these patients are encountered in small numbers or infrequently. Clearer guidance and education is required to equip staff in the assessment and treatment of MSCC patients ^(10, 11)
- 5. To be aware of professional guidance where practice should be focused on enabling individuals, groups and communities "to change aspects of their person, the occupation, or the environment, or some combination of these to enhance occupational participation"** ⁽¹²³⁾
- 6. To promote regular reassessment and improved clinical vigilance by community based Occupational Therapists and Physiotherapists caring for patients with MSCC**
- 7. To provide evidence based guidance or best practice guidance (in the absence of evidence) on the Occupational Therapy and Physiotherapy assessment and treatment of patients with MSCC, who are seen in the community** - While the NICE guideline (2008) on 'Supportive Care and

Rehabilitation' states the need for early access, focus on goals and outcomes and availability of specialist rehabilitation services, it lacks details on specific physiotherapy and occupational therapy assessments and treatments for patients who are based in the community

8. **To educate the wider multidisciplinary team in referral, diagnosis, assessment, treatment, clinical vigilance and rehabilitation of patients who have developed MSCC**

9. **To minimise disability and optimise quality of life (QOL) and survival in MSCC patients who have a limited prognosis** - Most patients die from their underlying cancer within a year of diagnosis of MSCC ^(12, 13). Patients with more favourable prognostic indicators may survive beyond 2 years ⁽¹³⁾. Early referral, diagnosis and treatment are crucial in minimising disability and optimising quality of life (QOL) and survival when living with this life-limiting condition.

10. **To ensure consistent and improved standardised care in the assessment and treatment of patients based in the community who have a diagnosis of MSCC, across the region of Northern Ireland, in keeping with the National NICE recommendations** ⁽³⁾ - Currently there are no guidelines in Northern Ireland for MSCC for Occupational Therapists and Physiotherapists working in the community setting.

11. **To ensure there is clear guidance as the incidence of MSCC increases** - The number of patients with MSCC is set to rise as the median age of the population increases and cancer survival is extended with more effective treatments. It is therefore necessary to have clear guidelines for MSCC, in order to improve care.

Roles and Responsibilities

Community Occupational Therapists and Physiotherapists should have access to the guidelines to inform and educate their practice, as incidence of MSCC increases.

Policy Statement

1. The MSCC Occupational Therapy and Physiotherapy subgroup is committed to promoting safe and best evidence based practice in the assessment and treatment of patients who present with MSCC.

2. This guideline is compliant with:
 - NICE Guidance CG75 Metastatic Spinal Cord Compression: Diagnosis and Management of Patients at Risk of or with Metastatic Spinal Cord Compression (2008) ⁽³⁾
 - National Cancer Action Team: National Cancer Peer Review Programme, Manual for Cancer Services: Acute Oncology – Including Metastatic Spinal Cord Compression Measures (2013) ⁽¹⁴⁾

Guideline Methodology

The Terms of Reference for the Guideline

The Terms of Reference were initially developed by the Northern Ireland Cancer Network (NICaN) AHP MSCC Guideline Development Group (GDG):

The GDG was responsible for overseeing the production of GAIN Guidelines for the Assessment and Care Provision of patients with Metastatic Spinal Cord Compression (MSCC) by Occupational Therapists and Physiotherapists, in the Community setting. Key functions were:

- To identify the remit of the clinical guidelines
- To oversee the production of the guidelines in an agreed, consistent format
- To undertake the review and update of the clinical guidelines in an agreed timeliness with GAIN.

Development of the Guidelines

- The group oversaw the development of the guidelines in keeping with the methodology of GAIN
- Individual authors were responsible for the guideline they volunteered to write
- The guidelines were based on best available evidence including literature review
- Editorial responsibility is a continued part of the work of this group
- The content and timeframe for developing the guidelines was set by the Subgroup within the agreement with GAIN
- All draft documents were held on the NICaN SharePoint for ease of version control

Accountability, Responsibilities and Performance Management

- At the outset of this project the members of the NICaN AHP MSCC Community Guidelines Subgroup were accountable to both the NICaN AHP Group and GAIN. They were responsible for providing progress reports to both.

- As the project progressed management was assumed by GAIN / The Regulation and Quality Improvement Authority (RQIA)

Membership

- At least two Representatives from Belfast, South Eastern and Southern Health and Social Care Trust (there must be representation from Community Occupational Therapy and Physiotherapy)
- GAIN Manager/Review Directorate
- Patient Representative.

Meetings and Procedures

- The group held meetings as necessary, however unless agreed otherwise, meetings were held quarterly.
- Group members received written notice via email of the meeting in the form of the agenda and relevant papers, which were circulated at least five working days in advance of the meeting.
- Special meetings were called as necessary by either the Chair or at least two members of the group if it was determined that there were urgent matters to be considered. In such circumstances the written notice via email of the meeting may not have been less than 3 working days.

Involvement of Stakeholders

Key to the development of GAIN guidelines was the involvement of relevant professional and patient/carer organisations (See Advice for Guideline Development in Northern Ireland) document. A list of the GDG for the rehabilitation of patients with metastatic spinal cord compression guideline can be found in Appendix 8.

Needs Assessment

The need for these guidelines to be developed was identified following a meeting with Physiotherapy and Occupational Therapy representatives from the five Trusts within Northern Ireland, Marie Curie Hospice and The Northern Ireland Hospice.

As noted the incidence of MSCC developing as a consequence of the primary diagnosis is relatively rare. It is therefore important to have an evidence based resource to provide the guidance in identifying and managing those cases which may present in the community.

The community guidelines are intended to act as a companion document to the Guidelines for the Rehabilitation of Patients with Metastatic Spinal Cord Compression (MSCC) Assessment and Care Provision by Occupational Therapists and Physiotherapists in the Acute Sector (2013).

Who Developed the Guideline?

Overview

The development of this guideline was based upon methods outlined in the 'Advice for Guideline Development in Northern Ireland' document (see Appendix 10).

A team of health professionals, lay representatives and technical experts known as the GDG (see Appendix 8), with support from GAIN/RQIA, undertook the development of this clinical guideline.

The Guideline Development Group (GDG)

The GDG was recruited in line with the existing GAIN protocol as set out in the "Advice for Guideline Development in Northern Ireland Manual". Following the approval of the GAIN Operational Committee to fund this project, requests for nominations were sent to the main stakeholder organisations and patient organisations/charities.

The guideline development process was supported by GAIN/RQIA staff. At the start of the guideline development process all GDG members' interests were recorded on a standard declaration form that covered consultancies, fee-paid work, share-holdings, fellowships and support from the healthcare industry. At all subsequent GDG meetings, members declared new, arising conflicts of interest which were always recorded.

There were no conflicts noted during the duration of the development of this guideline.

Guideline Development Group Meetings

Following an initial planning meeting in September 2012, GDG meetings were held monthly between March 2013 and June 2016. During each meeting, clinical questions and clinical and economic evidence were reviewed, assessed and recommendations formulated. At each meeting patient/carer and service-user concerns were routinely discussed as part of a standing agenda item.

The Co-chairs divided the workload by allocating specific and relevant topics, of clinical practice to small GDG sub-groups in order to simplify the development process. These groups considered the evidence, as reviewed by the systematic reviewer, and synthesised it into draft recommendations prior to presenting it to the GDG as a whole.

Patient/Carer Representatives

Patient/carers representatives were invited to comment on the draft document.

Expert Advisers

During the guideline development, areas were identified which required expert input. These topics were addressed by Community Clinical Specialist Occupational Therapists and Physiotherapists. The topics were addressed by either the production of a position paper or a formal presentation by the recognised expert who had been identified via the relevant registered stakeholder organisation. All relevant papers are presented as part of the evidence review.

Peer Review

This guideline was peer reviewed and informed by Emma Hicks, Macmillan Clinical Specialist Occupational Therapist Shrewsbury and Telford Hospitals NHS Trust and Shona Underwood Macmillan Clinical Specialist Physiotherapist, Shrewsbury and Telford Hospitals NHS Trust.

Updating the Guideline

In keeping with GAIN requirements these guidelines will be reviewed in 2020 or sooner in light of any emerging evidence on the existing benefits and harms of interventions or changes in outcomes.

Funding

The GDG was commissioned by GAIN to develop this guideline.

Audit

Following a reasonable time of imbedding this guideline, the implementation and adherence of this guideline should be audited.

Search Methods for Identification of Studies

Occupational Therapy, Physiotherapy assessment, rehabilitation and management of MSCC, in the community setting evidence questions and tables have not been included within this document. They are available at www.rqia.org.uk.

Search Strategy

Electronic Searches

Electronic databases searched included MEDLINE, EMBASE, CINAHL, The Cochrane Collaboration, PEDro, OT Seeker, Web of Science and Scopus. (Search terms used can be viewed in Appendix 1)

Limitations were applied for English language, humans and adults, year of publication from 2010 to December 2015 (except if limited evidence was available and the year of the search had to be extended).

Reference List Searches

The references and citations of identified studies were searched for other potentially relevant studies.

Website Searches

Numerous websites were searched for relevant clinical guidelines. Searches were conducted for:

Local, regional, national and international guidelines on Spinal Cord Injury (SCI) (Evidence table)	www.rqia.org.uk
Local and regional guidelines for MSCC from Cancer Centres (Evidence table)	www.rqia.org.uk
Spinal Cord Injury Rehabilitation Evidence (SCIRE)	www.scireproject.com
National Institute for Clinical Excellence (NICE)	www.nice.org.uk
Scottish Intercollegiate Guidelines Network (SIGN)	www.sign.ac.uk
National Cancer Action Team (NCAT)	http://ncat.nhs.uk/
National Comprehensive Cancer Network	www.nccn.org/index.asp
Northern Ireland Cancer Network (NICaN)	www.cancerni.net
GAIN	www.rqia.org.uk

Study Selection Process

Initially, two review authors independently examined titles and abstracts to identify potentially relevant studies under the guidance of Health on the net Northern Ireland (HONNI), Queens University Belfast (QUB). Whilst there were no disagreements, a process existed to resolve any issues that may have arisen.

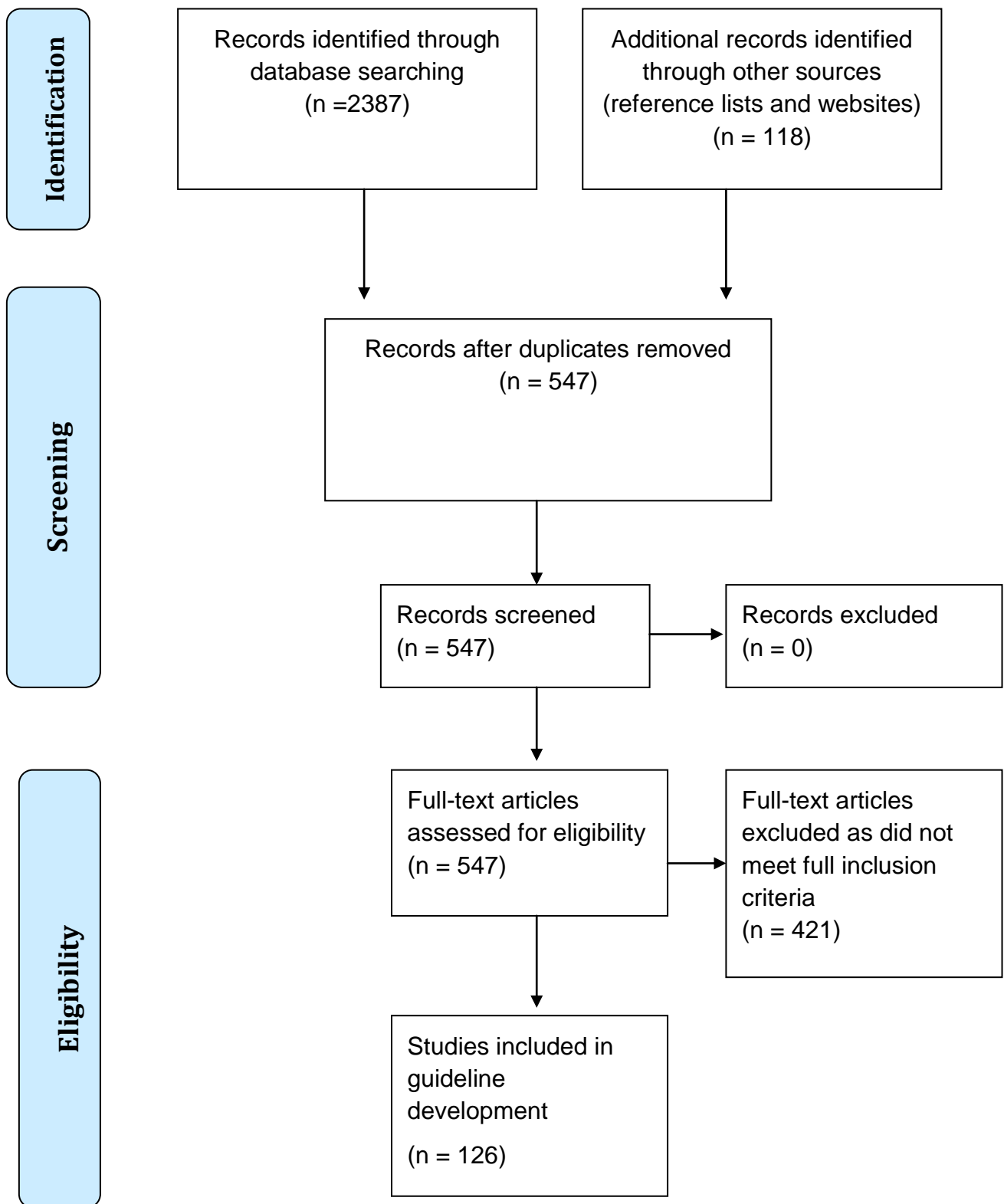
Studies included were relevant to MSCC, cancer, SCI, specific Physiotherapy and Occupational Therapy interventions or treatments with relevance to the community setting.

The full text of all relevant studies and material contributed by the Clinical Specialists from other Trusts were reviewed and subjected to the same inclusion criteria.

Data Extraction

Evidence tables were created through the extraction of selected articles. The quality of the included studies was assessed according to both the SIGN and Sackett scales. ^(15,122)

Figure 1: Study inclusion process - PRISMA flow diagram



REFERRAL

Referral for Management of Suspected MSCC

Community based Occupational Therapists and Physiotherapists may encounter patients at risk of developing or who have progressed to a Metastatic Spinal Cord Compression (MSCC) as a consequence of their primary diagnosis, or a first presentation with no known history of cancer and/or disease progression. ⁽³⁾

Note:

Diagnosis is based on MRI findings. National Institute for Health and Care Excellence (NICE) MSCC guidelines (2008) ⁽³⁾ state that an MRI should be done within one week for patients with spinal pain suggestive of spinal metastases. For patients with spinal pain and neurological symptoms suggestive of MSCC, MRIs should be done within 24 hours.

Urgent onward referral for appropriate medical management (via the patients General Practitioner and then onwards through the Acute Oncology Service), should be made if any of the following are observed:

Red flags including:

- **The four cardinal signs and symptoms of MSCC:**
 1. Pain (progressive or different from usual)
 2. Motor Dysfunction
 3. Sensory Dysfunction
 4. Bladder and Bowel Dysfunction ^(3,4,5,8,17)
- History of cancer especially high risk cancers e.g. lung, breast and prostate cancer or bone metastases

MSCC can cause:

1. Pain

- Pain is the earliest symptom of MSCC which is often present a number of weeks (median 6-8 weeks) before MSCC is diagnosed, in the absence of other symptoms ^(7,18) It may be a new pain or pain that has changed in character in patients with pre-existing chronic pain ^(4,17).

- It can be local neck or back pain or radicular pain, radiating to the limbs (arms or legs) or as a tight band around the chest or abdomen (the site of the pain will depend on the level of compression) ⁽⁵⁾
- It has a mechanical element and is often made worse e.g. by movement, coughing, sneezing and straining ⁽⁵⁾
- It is often unremitting and associated with anguish and despair. Typically, it escalates and is difficult to control despite increasing opioids ⁽⁴⁾
- It can be worse at night interfering with sleep ^(3, 18)

2. **Motor Dysfunction**

- Unsteadiness, difficulty walking and legs giving way
- Ataxia and loss of coordination
- Muscle weakness or paralysis ^(3,4,5,8,17)

3. **Sensory Dysfunction**

- Paraesthesia (pins and needles or tingling)
- Anaesthesia (numbness or diminished/loss of sensation) to touch, pain and temperature
- Hypersensitivity
- Proprioceptive impairment ^(3,4,5,8,17)

In some cases, sensation may be left intact ⁽²⁾

4. **Bladder and Bowel Dysfunction**

- Constipation
- Urinary Retention
- Incontinence ^(3,4,17)

Altered bladder or bowel habit from usual - some cancer patients may already have problems as a result of their primary cancer or treatment.

Referral to Physiotherapy and Occupational Therapy

Where hospital admission has been indicated, these patients should be referred for assessment and treatment by Occupational Therapists and Physiotherapists, within that setting. ⁽¹⁹⁾

Formal referral to Community based Occupational Therapy and Physiotherapy prior to discharge from the acute sector (secondary care), needs to be timely and appropriate, and is recommended to facilitate complex discharge planning. Discharge planning meetings should include community based therapists to ensure a coordinated approach to the transition from the acute hospital setting to the patient's preferred place of care. This will assist in the management of the patient's expectations of therapy and facilitate a coordination of service provision. The patient's consent must be gained before referral to community services, or consent from those acting on behalf of those who may not have mental capacity (in accordance with Health and Social Care Trust (HSCT) Policy).

There are a number of different Occupational Therapy and Physiotherapy services available within the community varying across the Region. Information and methods of referral on these can be accessed by searching Clinical Support Services at: <http://survivorship.cancerni.net/about>

It is important to note that some patients and families/carers, may not wish to have engagement with services, and may provide care from within their own support mechanism. In these instances, the patient and carers should have information about support services available in their locality, and how to access them.

ASSESSMENT

On assessment, if the community Occupational Therapist and Physiotherapist identify 'Red Flag' symptoms, an urgent referral for medical assessment is essential.

This is a medical emergency and requires immediate medical input (GP) ⁽²⁰⁾.

If onward referral is recommended, patient's consent is required.

It is important throughout the assessment and treatment process that the patient and family expectations are managed with cognisance given to the impact of this life limiting diagnosis and the subsequent levels of disability. The community Occupational Therapist and Physiotherapist should communicate with the patient and family in an open and sensitive manner.

Patients should be prioritised as per Trust guidelines and initial contact made in response to the referring information and/or pre-discharge contact with the acute team.

It is essential that there is co-ordinated team working with community staff involved with the patient's care – e.g. Social Workers/Care Managers, District Nurses, Community Hospice Nurse Specialists (Northern Ireland Hospice CNS/Macmillan CNS) and other Allied Health Professionals.

A comprehensive assessment should be made of:

Pain

Pain assessment should be carried out as part of the initial assessment and reviewed at each subsequent visit. All members of the multidisciplinary team involved with the patient can contribute to this assessment. When appropriate, onward referral should be made to GP, Community Hospice Nurse or District Nurse to reassess pain management.

A formalised pain assessment tool should be used in partnership with the patient to obtain a comprehensive assessment of each individual site of pain identified. This should take account of the following:

- Location & type of pain (body chart – See Appendix 3)
- Onset of the pain

- Duration of pain
- Character of the pain - is it constant or intermittent?
- Description of pain (“burning”, “shooting”, “a tight band”)
- Severity/intensity (Visual Analogue Scale (VAS))
- Aggravating factors (lying down, coughing, sneezing, straining)
- Relieving factors (positional, sitting up or lying down, medication)
- Functional effects (i.e. interference with activities of daily living)
- Nocturnal pain
- Psychosocial factors
- Current medication and any toxicity.

Neurology

Examine both sensory and motor function

Assess Sensation and Proprioception (see dermatome chart, Appendix 3) ⁽²⁰⁾

- Light touch
- Sharp/blunt – pin prick
- Joint proprioception – bilateral great toe position

Assess Motor function

- **Muscle power:** see Myotome chart ⁽²⁰⁾ and Oxford classification (Appendix 4a & 4b)
- **Muscle tone:** flaccidity or spasticity see Modified Ashworth Score (Appendix 5) ^(17,21).

Consideration may be given to the use of the American Spinal Injury Association (ASIA) Scale as a multidisciplinary tool ⁽²²⁾.

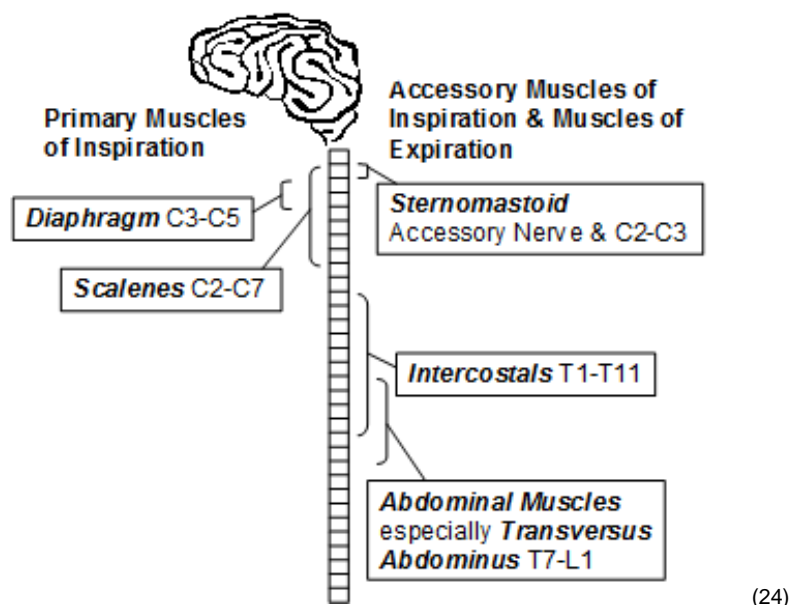
Spinal stability and mobility recommendations

Confirmation regarding spinal stability and mobilisation/rehabilitation recommendations need to be clarified by a medical source (Orthopaedic surgeon/ Oncologist/GP) to ensure safe handling and protection of the spine. This information should be transferred from the acute sector therapists to the Community Therapists on referral.

Respiratory function

Respiratory complications are a leading cause of morbidity and mortality in people with Spinal Cord Injury (SCI) (23, 26, 26, 86). The extent and level of the MSCC is significant in determining the degree of respiratory dysfunction, confounded in some patients by underlying lung disease (19).

Figure 2: Innervation of the Respiratory Muscles



Effects of MSCC on Respiratory System

Dependent on the level and completeness of the spinal cord compression, it could cause:

- Inspiratory and expiratory muscle dysfunction
- Reduced lung volumes
- Reduced lung compliance
- Impaired cough flow
- Airway hyper-responsiveness
- Mucus hypersecretion (23,24,27,28)

Putting the patient at risk of:

- Increased work of breathing
- Ineffective sputum clearance and sputum retention

- Inspiratory muscle fatigue
- Respiratory compromise
- Atelectasis
- Respiratory infection (3,23,24,27,28)

Assessment of the following should be considered:

- Pulmonary Function Tests e.g. vital capacity (VC) or Forced Expiratory Volume in one second (FEV₁) (25,28,29,30)
- Peak Flow Measurements e.g. peak cough flow (peak flow <160l/min = airway secretions cannot be effectively cleared) (27, 28).
- Clinical observations including respiratory rate, pulse rate, temperature, blood pressure, SaO₂ (25,27,30)
- Arterial blood gases (25,29,86)- if ABG's are considered then liaison with GP would be indicated
- Recent/baseline thoracic imaging e.g. CXR (11).
- Auscultation: air entry & added sounds (e.g. crackles/wheeze) (28,86)
- Breathlessness Assessment (28,30)
- Breathing pattern and diaphragm function (25,28,86)
- Cough mechanism (25,86)
- Sputum analysis (amount, viscosity, colour and signs of retention) (28,86)
- Oxygen Therapy (O₂) needs (FiO₂ and inspiratory flow rate) (86)
- Inhaler/Nebuliser Therapy needs
- Analgesia management (29)
- Smoking history (30)
- History of chronic respiratory condition (86)
- Exercise tolerance (30)
- Positioning/positional influences on respiration (28)

Associated lung pathology e.g. rib metastases, lung metastases, malignant pleural effusions should also be considered.

Signs of Autonomic Dysreflexia ⁽²⁰⁾

Patients with MSCC above T6 should be monitored for signs of autonomic dysreflexia and managed appropriately.

Autonomic dysreflexia is the autonomic response to painful (noxious) stimuli perceived below the level of the lesion and is a potential complication for all patients with spinal cord lesions above the level of T6. The most common stimulus is blockage of the urinary catheter. This problem manifests as acute hypertension. Systolic blood pressure can easily exceed 200 mm/Hg. Un-resolved; it can cause fatal cerebral haemorrhage. This reflex response is usually suppressed during the period of spinal shock for an initial, acute admission.

The most common presenting symptoms of autonomic dysreflexia are:

- Severe hypertension
- Bradycardia
- 'Pounding' headache
- Flushed or blotchy appearance of patient's skin above the level of the lesion
- Profuse sweating above the level of the lesion
- Pallor below the level of the lesion
- Nasal congestion
- Non-drainage of urine (urinary obstruction being the most common cause).

This is a medical emergency and requires immediate medical input (GP) ⁽²⁰⁾

Risk Assessments

Risk assessments should be completed in relation to moving and handling, environment and behaviour as per relevant Trust guidance. Consideration should be given to carrying out multi-disciplinary assessments and reviews with patient's care staff for monitoring and continuity of care, as the patient's condition may change rapidly. All assessments should be formally recorded and shared with staff working with the patient. A copy should be left in patient's home accessible to all domiciliary staff/carers/family, as per Trust Guidelines.

Assessment of Home Environment

It is important to provide a comprehensive Occupational Therapy assessment of the home environment in light of the patient's functional ability, once determined. The Occupational Therapist can prescribe necessary equipment based on local protocols and can also make recommendation for minor adaptations such as grab or hand rails.

If the patient is:

- Unable to access facilities in their current home it may be appropriate to consider adaptation to the existing home. The Occupational Therapist can make recommendations in line with local protocols. Written consent for minor adaptations carried out by the HSCT may be required from private landlords. Alternatively rehousing through the Northern Ireland Housing Executive (NIHE) may be considered.
- Requiring financial assistance, they can be directed towards Disabled Facilities Grant through NIHE if they live in a privately-owned property or direct recommendations can be made to NIHE or local Housing Associations on behalf of tenants living in rented properties.

As MSCC is a complication of advanced cancer the patient's prognosis should be considered before recommending such alterations.

If it is appropriate and timely to progress with a major adaptation the Occupational Therapist must monitor and review such cases on a regular basis to ensure the patient's condition remains stable. If there has been any further deterioration this would require a reassessment.

Some patients will want to progress with adaptation privately and the Occupational Therapist can offer advice, detailed specifications and provide documentation to support exemption from VAT payments where applicable.

<http://www.nihe.gov.uk/adaptationsdesignscommunicationstoolkit.pdf>

Mobility and Activities of Daily Living ⁽⁴⁾

This assessment should be guided by clarification of spinal stability and mobility recommendations (See Appendix 6) and limb strength. This should include assessment of:

- Joint range of movement (ROM) (active/passive) and muscle length
- Balance (sitting/standing if appropriate)
- Posture and alignment
- Risk for moving and handling ⁽¹⁷⁾ A risk assessment for moving and handling should be carried out for each patient per HSCT policy
- Functional mobility e.g. bed mobility; lying to sitting; sitting balance; sitting to standing; standing balance; transfers; walking; wheelchair mobility; stairs; steps; kerbs; indoor and outdoor mobility as appropriate
- Activities of Daily Living (ADLs):
 - Personal Activities of Daily Living (PADL): feeding, hygiene, toileting, bathing and dressing
 - Instrumental Activities of Daily Living (IADL): cooking, housekeeping, laundry, use of transport, managing money, shopping and managing medication
 - Work and leisure pursuits.

Fatigue/Exercise tolerance

Fatigue is a common symptom experienced by patients with cancer diagnoses. It is a multi-dimensional symptom encompassing physical and mental aspects which can severely compromise quality of life. All patients with cancer related fatigue should be screened, assessed regarding severity and impact of fatigue and offered management strategies to cope. There are many single, multi-item and multi-dimensional tools that have been developed to assess and measure fatigue.

Assessment should include:

- 0-10 numeric rating scale - used for screening (a score of 1-3 indicating mild fatigue; 4-6 indicating moderate fatigue and 7-10 indicating severe fatigue).
- When fatigue is rated as moderate to severe, a more focused history and physical examination should be conducted.

This will require input from the wider multidisciplinary team and management strategies are dependent on the patients' clinical status, disease stage and contributory factors. ^(31,32, 33)

Pressure ulcer risk and skin integrity

Consider the impact of the following factors on the individual's risk of pressure ulcer development:

- Nutritional indicators e.g. anaemia, low haemoglobin and serum albumin levels, poor nutritional intake and weight
- Factors affecting perfusion and oxygenation e.g. diabetes, cardiovascular instability, low blood pressure, ankle brachial index and hypoxia (low SaO₂)
- Skin moisture
- Advanced age
- Friction and shear
- Reduced mobility: Those individuals who are bedfast and / or chair fast are to be considered at risk of pressure ulcer development ⁽³⁴⁾
- Impaired or loss of sensation
- Skin Changes at Life's End (SCALE): At end of life, failure of the homeostatic mechanisms that support the skin can occur, resulting in a diminished reserve to handle insults such as minimal pressure⁽³⁵⁾

Initial assessment should document any areas of poor skin integrity, pressure ulcers, impaired sensation and post-surgical wounds.^(36,37,38) This should be repeated regularly and as frequently as is required by the individual's condition. ⁽³⁴⁾ The skin

should be inspected frequently for signs of redness in individuals identified as being at risk of pressure ulceration. ⁽³⁴⁾ Areas of special concern include the sacrum, coccyx, ischial tuberosity's, greater trochanters, scapulae, occiput, heels, digits, nose and ears ⁽³⁵⁾ www.publichealth.hscni.net

Repositioning

The need for frequency of repositioning should be assessed in all “at-risk” individuals, taking into consideration the individual’s tissue tolerance, spinal stability, level of activity and mobility, general medical condition, overall treatment objectives, assessment of the individual’s skin condition, general comfort and the surface in use ⁽³⁴⁾

Swelling/DVT/DVT risk/Lymphoedema

Risk factors for DVT have been identified as: history of venous thromboembolism; thrombophilias; cancer; chemotherapy; combined oral contraceptives; hormone replacement therapy; varicose veins with phlebitis; obesity; immobility (>3 hours); trauma; before and after surgery and over 60 years, and should be assessed. ^(39,40)

Baseline skin observations, girth and length measurements should be recorded. ⁽³⁸⁾ A swollen limb will only be apparent approximately 10 days after the clot has formed. ⁽²⁰⁾ A sudden, unexpected pyrexia may be a diagnostic indicator of early DVT formation ⁽²⁰⁾

Any contraindications to Graduated Compression Stockings (GCS) should be assessed ⁽³⁹⁾. GCS should be avoided in peripheral vascular disease (PVD) ⁽³⁹⁾ and patients with pressure ulcers and dermatological conditions. ⁽⁴¹⁾

Consult the anti-embolism Trust policy or NICE Venous Thromboembolism Guidelines (2012) ⁽³⁹⁾ or SIGN Venous Thromboembolism Guidelines (2010) ⁽⁴⁰⁾

Bladder & Bowel function

Any urinary or faecal incontinence, constipation, urinary retention, associated pain, infection issues, fluid restrictions or catheterisation should be clarified and documented to provide a baseline.⁽³⁾

Social and Occupational factors

The Occupational Therapist and Physiotherapist should establish previous functional level, life roles, values, support and relationships and services in place, as reported by the patient and carers. The understanding and expectations of the patient and their family regarding their current level of ability and potential for rehabilitation are an integral part of assessment, leading to agreed realistic goals of treatment. Joint Physiotherapy and Occupational Therapy assessment will facilitate this.

Psychological Well-being

Consideration should be given to the patient and family's concerns, emotional concerns, distressing issues, mood and interests, anxiety, adjustment to illness and treatment, strengths and existing support. This may include discussion on intimate relationships determining the importance to the patient and their partner.

The Occupational Therapist and Physiotherapist will communicate with patient and family in an open and sensitive manner, providing emotional and psychological support within their limits of competence.

They should liaise with other members of the multi-disciplinary team to identify the availability of local support services e.g. Northern Ireland Hospice Community Teams; Hospice Day Therapy services; carers assessment; referral for complementary services; spiritual support; counselling services and social support. Social support may include services such as pre and post bereavement counselling. Staff should familiarise themselves with the specific referral processes to access Trust based services.

Cognitive Factors

The causes for alteration in cognitive functioning in cancer patients are varied. Potential causes can include:

- Primary or secondary cancers of the brain
- Side effects of therapeutic interventions for malignancy
- Metabolic, haematological or infectious processes
- Nutritional deficiencies
- Side effects of medications
- Co-morbidities; age, psychiatric disorders, depression, dementia, fatigue, sleep disturbances and the distress associated with a diagnosis of cancer ⁽⁴²⁾

The Occupational Therapist may use a combination of standardised and non-standardised outcome measures, combined with observation and clinical judgement to assess cognitive function. They should consider problems in understanding, confusion or disorientation, memory loss and hearing, vision and speech problems.^(21,43, 44) If there are reversible causes of reduced cognition these require appropriate medical management eg, infections, hypercalcaemia, medication side effects. If findings fall outside the therapist's limit of competence, in this specific area, then onward referral should be made to the relevant service in accordance with local Trust procedures.

Supportive care and rehabilitation for patients with MSCC

Clinical vigilance should be exercised throughout rehabilitation with regular assessment and documentation of pain and neurology in the patient's clinical notes, in accordance with local Trust policy.

Confirmation regarding spinal stability and mobilisation/rehabilitation recommendations need to be clarified by a medical source (Orthopaedic surgeon/ Oncologist/GP) to ensure safe handling and protection of the spine.

Any worsening of pain and neurological symptoms (power and sensation) should be recorded, reported and further medical advice sought - it may be a sign of progression of spinal metastases, increasing cord compression or spinal instability.

It is accepted that some MSCC patients will be assessed as having an unstable spine. Owing to the short life expectancy and quality of life issues they may, however, be managed as having a stable spine. This decision will be made following discussion with the patient, family (ensuring they understand the level of risk involved), agreed with the GP and/or Consultant Oncologist and documented.

Red Flags

Signs of spinal instability or increasing spinal cord compression

1. Worsening pain
2. Worsening sensation
3. Increasing muscle weakness
4. Worsening mobility and balance
5. Worsening bladder and bowel function

Clinical vigilance and thorough monitoring of these signs are required during rehabilitation, returning patients to supine lying to limit neurological damage whilst medical advice is sought. ^(3, 4, 5, 8, and 17)

Additional considerations/precautions/contra-indications during rehabilitation of MSCC patients:

- Other sites of spinal metastases and pending sites of MSCC
- Other sites of bony disease and pathological fracture risk or existing pathological fractures
- Impaired cardiac function
- Unstable heart rate (HR) (abnormally high or low)
- Unstable blood pressure (BP) (abnormally high or low), dizziness or postural hypotension
- Motion sickness
- Visual disturbance or loss
- Signs of DVT or pulmonary embolus
- Signs of autonomic dysreflexia (characterised by raised BP, decreased HR, headache, blotchy flushed skin, sweating above the level of the lesion, pallor below the level of the lesion). (see page 26)
- Confusion
- Drowsiness
- Pressure ulcer/skin breakdown
- Chronic history of poor or absent sensation
- History of falls or recent falls and any possible injuries sustained
- Increased bleeding risk/low platelets
- Low haemoglobin
- Shortness of breath (SOB)/hypoxia
- Arthritic joints/restrictions in range of movement (ROM)
- Recent surgery
- Poor premonitory mobility/prolonged immobility

- Chronic history of muscle weakness

Any of the above will have an impact on patient's ability and treatment should be adjusted accordingly.

Pain Management

For those patients who experience and/or anticipate pain on movement, administration of pain relief prior to movement should be considered and break through analgesia provided as appropriate ⁽³⁾

If concerns remain regarding pain management, onward referral should be made to the GP, community hospice nurse or district nurse for reassessment.

A range of non-pharmacological interventions can be useful in managing pain: ⁽⁴⁵⁾

- Gentle limb movement and exercise ⁽⁴⁶⁾
- Positioning, ensuring the spine is in appropriate alignment ⁽⁵⁾
- Massage ⁽⁴⁶⁾
- Bracing and Collars ⁽²⁰⁾
- Relaxation ^(46,47)
- Transcutaneous electrical nerve stimulation (TENS) ^(46,48)
- Acupuncture ⁽⁴⁸⁾
- Heat (contraindicated over the site of the cancer and pressure ulcers) ^(5,48)
- Cognitive Behavioural Therapy (CBT) aimed at modifying dysfunctional pain cognitions and coping abilities ^(46,49,50)
- Motivational interviewing ⁽⁵¹⁾

Graduated/Controlled Mobilisation

Best practice guidelines advocate graduated mobilisation of patients with MSCC, based on MRI results and formal medical advice to mobilise, with strict pain, neurological assessment and clinical vigilance to monitor for signs of spinal instability. ^(3,4,8,17,21,41,52,53,54,)

Graduated mobilisation should be commenced by appropriate skilled Physiotherapy, Occupational Therapist/professional staff, capable of assessing pain and

neurological symptoms. This may have commenced prior to discharge into the community sector and should be integrated into the management and rehabilitation process. The Physiotherapist and Occupational Therapist will make recommendations to staff and carers for safe transfers/repositioning which involve verticalisation.

Bracing (Patients who may benefit from bracing)

Cervical spine collars and spinal bracing significantly reduce spinal motion, stabilising the spine, protecting the spinal cord ^(55, 56, 57) and may reduce spinal pain. Collars and spinal bracing may be prescribed or considered by the Physiotherapist and medical team to facilitate the patient mobilising (see table 1 for indications). Patients may have already been assessed/prescribed and fitted with a collar/brace following surgical intervention. Where necessary appropriate referral should be made and specialist advice sought from the Orthotic/Orthopaedics department (Hospital based). A small stock of cervical collars should be held for ease of accessibility – this will depend on local Trust policy. Owing to an extensive range of thoracic and lumbar spinal bracing, it may be impractical to maintain an adequate range of braces. Measuring and ordering should be done on an individual basis.

Table 1: Possible indications for collars and spinal bracing for mobilising

Patients with unstable MSCC but not suitable for surgery ^(3,4,5,17,20,41,53,58,59)
Patients with unstable MSCC but not suitable for surgery, with significant preservation of power and sensation, for protection of neurology
Patients with significant mechanical pain – to reduce pain ⁽¹⁷⁾
Post-operative spinal surgery patients as per consultant recommendations

Patients who have been prescribed collars are at risk of skin breakdown. This may occur at the shoulders, occiput, chin and back, generally from plastic edges not being entirely covered by foam. Changing of the pads every 24 hours and inspecting and cleaning every 12 hours is recommended.⁶⁰⁾ Radiotherapy skin markings (if not tattooed) may however limit cleaning of the skin, if the patient is still undergoing active radiotherapy treatment.

Verticalisation – graduated sitting up

When the patient has achieved sitting upright in bed with no adverse effects on pain and neurology, unsupported sitting, transfers, sitting in the chair or wheelchair and more active mobility and rehabilitation out of bed can be commenced depending on the patient's presenting symptoms ^(3,5, 8,53,61).

Patients should be facilitated from lying to sitting in bed, through side lying (modified log rolling) to maintain spinal alignment and reduce pain.

Joint assessment by the Occupational Therapist and Physiotherapist to assess sitting balance and tolerance of postural change will influence seating recommendations for the home setting.

Seating Assessment

The Occupational Therapist will assess and advise on appropriate seating to facilitate function in activities of daily living and social interaction within the home environment.

Static Seating

The Occupational Therapist will assess and advise on the seat width, depth, height and support required to facilitate ease of sit/stand transfers.

Critical Measurements will be recorded to guide prescription of seating available to the patient in their home environment, (which may be available from the HSCT stock as permits, regional variations on provision and loan of equipment conditions may exist.) The assessment and recommendation will consider the patient's skin integrity and risk of developing pressure areas due to skin compromise associated with the potential of prolonged sitting. On identifying this risk, the Occupational Therapist will assess for the appropriate level of pressure relieving cushion available from HSCT stock, and integrate provision into the seating assessment, as per local HSC Trust policy

Additional factors which will influence the seating assessment should include the patient's ability to tolerate postural change, respiration, level of fatigue, cognitive

state, continence, comfort and environmental considerations – circulation space around and within the home.^(34,62,63)

Patients should be encouraged to sit out incrementally and also to mobilise safely, to reduce and alleviate pressure from sitting for prolonged periods, and to avoid deconditioning.

Functional/Postural seating

Following assessment for dynamic seating, the Occupational Therapist may prescribe appropriate seating as per HSCT guidelines.

Chairs may include those with a rise/recline function, to assist the patient in transferring from sit to stand, and which may incorporate leg rest elevation. Due diligence must be taken when assessing the need for these chairs with respect to the recommended use. They may be considered for the management of severe fatigue and for quality of life for patients at end of life care.

Riser – recliner chairs are not recommended as an alternative to a sleeping system.

Review and monitoring of seating requirements should be carried out on a regular basis, as the patient's seating needs will change.

Assessment indicating provision of seating and pressure relieving cushions which are not held on stock may precede using local HSC Trust procurement arrangements.

Level Three Seating Assessment

Postural Seating/Tilt and Recline: Assessment for Level Three seating should follow the HSCT Criteria and Guidelines, and procurement arrangements made if provision is unavailable from stock. Patients requiring this level of prescription for seating tend to require hoisting for transfer.

Patients may view this assessment and recommendation for provision of seating as an intrusion into their domestic arrangements⁽¹¹³⁾. They may wish to pursue private purchase, if appropriate seating is not available in the home. In some instances,

financial assistance may be available through grant application to voluntary agencies and charities.

Retraining Function

The degree of functional independence achievable post cord compression is dependent on the level and completeness of the spinal cord compression and resulting motor weakness, sensory dysfunction and pain. Age and other medical conditions can also impact on an individual's functional performance (see Appendix 3 & 4a, for motor and sensory levels of innervation).

Bed mobility

Patients should be taught and encouraged to practise bed mobility in order to maximise independence, whilst still monitoring the presence of pain and altered neurology e.g.

- Rolling in bed
- Moving up, down and across the bed
- Lying to sitting to standing
- Getting into and out of bed

Using bridging as a technique to facilitate bed mobility should be done with caution, depending on the site of the MSCC. The level of assistance, moving and handling devices required and the need for a profiling bed should be assessed and service providers contacted as per individual Trust policy ^(4, 5, 53, 59)

Functional Transfers (e.g. Bed to Chair)

A manual handling risk assessment should be carried out considering: assistance required, transfer technique, moving and handling devices required, weight, size, mobility, space available, pressure relief and skin care, sitting balance, cognitive status and fatigue. See local trust care pathway for the moving and handling of patients.

Table 2: Possible transfer methods in rehabilitation (guidance only) ^(4, 64):

Activity Level	Possible transfer method in rehabilitation: e.g. bed to chair, wheelchair, commode/ toilet and shower chair transfers
No sitting balance ± poor upper limb activity	Hoist plus assistance of two minimum (if there is no improvement in sitting balance or board transfers over one week of rehabilitation, it is likely that a hoist will be required for transfers)
Some or independent sitting balance, reasonable upper limb strength but significant loss of leg power (<3) / unable to stand.	Sliding board transfers (with side off chair) ± assistance. Hoist will be required if slide board not available, or technique of transfer unsafe
Sitting balance/ ≥ 3 leg power <ul style="list-style-type: none"> • Unable to step with assistance • Able to step 	Standing transfer aid ± assistance Standing transfer with side off chair ± assistance. Sliding board transfers (with side off chair) With assistance, supervision or independently Walking aid (e.g. pulpit, zimmer rollator (ZR), zimmer frame (ZF), delta rollator (R), stick, crutch.

The Occupational Therapist and Physiotherapist will be involved in the assessment and re-education of transfers and will make recommendations for safe transfers regarding equipment and assistance required. Training will be provided to staff, patients, families and carers on safe transfer techniques and use of equipment.

Functional transfers to the bed, chair, commode, toilet, wheelchair, shower chair and bath should be considered ^(59, 61).

Refer to local Trust guidance regarding information and documentation to be provided to carers re: written/visual instruction of recommendations made and whether this is to be placed in patient's records in their home. This can be

particularly important in the community when carers assisting the patient may change.

Review of manual handling/moving and handling recommendations should be made according to local Trust guidance in addition to each patient's specific circumstance. Manual handling recommendations should be made with cognisance of disease trajectory and an understanding of how manual handling needs will change as the patient's illness progresses. The suitability of the patient's environment to accommodate change in manual handling needs and equipment required should be considered at all times especially if the patient's current environment is their preferred place of care and where they would like to remain if possible.

Advanced transfers

As required, advanced transfers should be taught and practised ^(4, 41, 58, 59, 61) e.g.:

- 180° transfers
- Floor to chair transfers (considered if patient at risk of falls)
- Height difference transfers
- Car transfers

Balance and Gait Re-education

Gait re-education should be commenced in order to restore independent mobility if patients have adequate lower limb power (see below). Wheelchair use may be considered in conjunction with ambulation or as the primary method of mobility.

- Patients with Grade 3 or above bilateral leg power:
 - Sit to stand, standing balance and stepping activities, may be considered for gait re-education and step/stair practice.
 - Provision of a suitable walking aid may facilitate independent mobility,

Strong evidence exists to support conventional Physiotherapy gait re-education, body weight support gait training (with both methods being equally effective). Improvements in walking ability, speed and distance, lower limb strength, balance and psychological well-being are widely reported with gait re-education ^(65, 66, 67, 68, 69)

For stairs: additional rails, assistance, use of a stick or crutch, altered technique or elimination of use of the stairs, (depending on result of environmental assessment) may be required to ensure safety. A feasibility study may be undertaken to establish the need for a through floor lift or modifications to ground floor accommodation.

- Patients with below Grade 3 bilateral leg power:
 - wheelchair is likely to be the safest method of mobilising
- Patients with unilateral lower limb weakness should be assessed and treated on an individual basis

Standing aids may also be used to stretch the lower limbs in tetraplegic and paraplegic patients as appropriate. Indications for use of such standing aids should be assessed and service providers contacted as per individual Trust policy

It may be necessary to monitor the patients' blood pressure (particularly with symptoms of dizziness), as postural hypotension may occur especially in T6 and above MSCC patients, in standing.⁵⁸⁾

Wheelchair Use

Clinical Guidelines for the Provision of Wheelchairs

If a patient is unable to mobilise due to insufficient lower limb power or unable to mobilise efficiently enough for function, then wheelchair mobility is indicated.

A comprehensive wheelchair assessment will be carried out at a mutually agreed time and place, and an appropriate wheelchair will be prescribed for physical and social needs in relation to the eligibility criteria and available products on the NHS contract.

Each of the five Health and Social Care Trusts in Northern Ireland has their own Wheelchair Resource Team. Occupational therapists can refer service users to their local Wheelchair Resource Teams using individual Trust referral protocols.

For more complex wheelchair prescriptions each Trust has access to the Regional Bio-Engineer based at the Regional Disablement Services within the Belfast HSCT. If a referral to the Bio-Engineer is being considered this should be discussed with the local Wheelchair Resource Team prior to completion of a referral. Once agreed, the referral to the Bio-Engineer should proceed and the referring occupational therapist will be asked to complete the Regional Disablement Referral form and process this in line with their Trust Protocols.

When a service user requires a short-term loan wheelchair

Wheelchairs will only be supplied to service users who need them for permanent use, i.e. longer than six months. Commissioning Trusts have arrangements locally for short term wheelchair use through British Red Cross.

Patients and carers can contact the Red Cross directly, (there may be a cost/donation associated with this). Shop Mobility and other private suppliers may also provide wheelchairs for short term loan.

Clinical Guidelines for the Provision of Wheelchairs in Northern Ireland are accessible via each HSC Trust Intranet.

Re-educating Activities of Daily Living

Patient's actual functioning can vary extensively as a result of the level and degree of the MSCC, and resulting motor weakness and sensory dysfunction. MSCC patients have advanced cancer so fatigue and pain will impact on ability. These symptoms should be managed using planning, prioritising, pacing and other energy conservation techniques.

The Occupational Therapist will assess and make recommendations for body positioning, adaptive techniques, appropriate equipment, clothing, advice for the carer and the need for assistance as indicated. There should be an on-going monitoring and review process in recognition of the potential for deterioration in functional ability.

Self-care – Washing/Dressing/Grooming

Patients with C3 – C4 cord compression can present as an incomplete compression. This group of patients can be mobile but with severely affected upper limb function (central cord syndrome) i.e. present with loss of upper limb function without lower limb paralysis

When in a supported position and assistance is provided in setting up specialised equipment, individuals with cord compression at C5, C6 - 7 can participate in:

- face washing
- brushing of teeth
- face shaving
- applying make-up
- haircare

Patients with C8 – T1 cord compression will have full upper extremity control and can have a more active role using upper limbs.

Patients with T2 – L1 lesions have greater potential to achieve trunk control. Lower thoracic level lesions are more likely to get increased trunk control e.g. T8/9 with some preservation of innervation of abdominals and back extensors. For those with

active trunk control they can be encouraged to participate fully in these tasks. Upper body personal care can be completed from a seated position, continuing to complete lower body tasks when in bed. ⁽¹²⁵⁾

Those with ≥ 3 bilateral leg power can benefit from personal care practice incorporating standing in a suitable safe environment.

Fatigue and pain can impact on ability. Management of these symptoms should be considered.

For those patients who require support to complete washing and dressing a care package may need to be arranged. If family/carers wish to take on this role they should be supported to develop the skills to competently carry out the task. ^(70,72)

Bathing/Showering

The Occupational Therapist will assess:

- the quality of performance of bathing and showering activities as appropriate
- identify the need for adaptive equipment to facilitate independence as required (those with diminished sensation will also require close monitoring of the water temperature by a carer).
- assess the environment and attempt to meet the patient's needs within this.

<http://www.nihe.gov.uk/adaptationsdesignscommunicationstoolkit.pdf>

Patients with poor trunk control may require access to a level access showering facility such as a wet room, to accommodate tilt in space equipment. The Occupational Therapist will be able to offer timely advice and support, regarding adaptation and practical information, particularly with regard to recommended specifications required for any work identified.

Discussion and information will allow the patient and their family to make an informed decision whether or not to proceed with major adaptation, through the Disabled Facilities Grant (through the Northern Ireland Housing Executive (NIHE));

private installation; recommendation to NIHE; or housing association if a tenant in public sector housing.

Toileting

Once the patient's functional ability has been determined, access to toilet facilities should be considered. The patient may be able to use the existing toilet independently or with adaptive equipment or minor adaptation.

If the toilet is inaccessible to the patient, use of a commode may be considered or access to toilet facilities addressed as part of a major adaptation.

Patients may require assistance to tend to personal hygiene and if necessary a wash and dry toilet could be considered

Feeding

Patients with high cord compression can experience difficulties with upper limb function. The Occupational Therapist will consider functional positioning and assess the need for feeding and drinking equipment and wrist/hand splints to facilitate independence.

If there are signs of aspiration and choking during feeding and drinking, the GP must be informed and also a referral to Speech and Language Therapy (SLT) should be requested ⁽²²⁾.

Meal Preparation and Home Management

The impact of MSCC and the subsequent changed role of the patient in the home setting should be considered before home management activities are addressed. The ability to perform activities will be dependent on the level of spinal cord compression; fatigue and pain (see Fatigue Management and Increased Exercise Tolerance, page 58). Occupational Therapy can provide the opportunity to practice skills and provide advice on adapting the home environment to enhance independence. This might include a perching stool if appropriate for energy conservation. Meal provision may be necessary as part of a care package or provision of family/carer support may need to be arranged.

Leisure

Opportunity should be provided to discuss and partake in leisure activities ^(5, 59). The potential to modify activities to allow participation ⁽²²⁾ and the use of door to door, wheelchair accessible taxis for transport should be explored.

Information regarding application to the 'Blue Badge Scheme' can be accessed at:

<https://www.nidirect.gov.uk/information-and-services/motoring.../blue-badge-scheme>

Information on leisure activities for people with cancer can be accessed at:

<http://survivorship.cancerni.net>

Physiotherapy Exercises

Strong evidence exists to support the use of exercise with patients who have sustained SCI, impacting on- cardiac, vascular ^(12,71), metabolic ⁽¹²⁾, bone ^{12,72)}, biomechanical/range of movement (ROM) ^(12,73,74), muscular ^(12,73,74,75,76), balance, functional ^(73,74,76), quality of life (QOL) ^(12,73,74,77) and also physiological benefits ^(73,74). Physiotherapy exercises are advocated in the rehabilitation of the MSCC patient largely to stretch muscles and joints, maintain ROM, strengthen muscle and neural pathways, promote circulation, encourage balance reactions, restore function, improve physical capacity, reduce fatigue, promote bone health and improve psychological wellbeing and QOL. Rehabilitation programmes can also improve life expectancy ^(78, 79).

When considering any exercise regime in the community setting it is important to ensure that the programme is tailored to the patient's personal priorities ⁽⁸⁰⁾. Goals should be set with the patient, family/carer and physiotherapist/multi- disciplinary team (MDT) ⁽⁸⁰⁾. Parallel planning of programmes should ensure there is an alternative exercise programme given for the days when the patient is feeling too unwell to carry out their full exercise programme ⁽⁸⁰⁾. The programme should be linked to function, to reduce fatigue and improve compliance. Co morbidity factors should always be considered e.g. pain, fatigue, nausea and dyspnoea.

Exercises may include static, passive, active assisted, active and resisted exercises, stretching techniques, balance exercises and Bobath techniques in various positions depending on the patient's muscle activity, spinal stability and pain ^(20, 58, 59, 81). Exercises for the trunk, upper limbs and lower limbs may be performed.

If the patient has the ability to stand and has the appropriate level of exercise tolerance, some exercises may be carried out in standing ⁽⁸²⁾.

Physiotherapy exercises should be performed at least once or twice daily within strict pain limits and with monitoring of pain, power and sensation. If movement worsens or there is an increase in neurological symptoms the exercises should be stopped and medical advice sought.

It is worth noting the environment in which the patient prefers to carry out their rehabilitative exercise programme. Some may prefer the home setting ⁽⁸³⁾ as others may benefit from a group programme where they can also receive psychosocial support e.g. day hospice.

All home exercise regimes should be reinforced with written instructions ⁽⁴⁾.

It is important for patients to get a balance between exercise and rest considering fatigue levels. Once a plateau has been reached, with regards to rehabilitation, exercise is for maintenance purposes. Patients should be given the choice of continuing to exercise or incorporating it into function to maintain their ability and hence quality of life.

Functional Electrical Stimulation (FES) of the muscles may also be a useful adjunct to exercise and movement. Evidence related to Spinal Cord Injury (SCI) exists to support its use in improving muscle strength and endurance and reducing muscle atrophy and in enhancing gait and functional recovery of movement. ⁽⁸⁸⁾

Precautions

Table 3: Precautions on exercise in the rehabilitation of the MSCC Patient

Based on expert opinion and best practice guidelines: (4, 20, 37, 41, 52, 58, 59, 61)

Physiotherapy exercises should be performed within strict pain limits and with monitoring of pain, power and sensation. Stop any activity worsening pain or neurology and seek medical advice.
Neck exercises should be avoided and care should be taken on activities involving head movement with MSCC of the cervical spine ^(41,59) ,
Back exercises should be avoided with MSCC of the thoracic, lumbar or sacral spine ⁽⁵⁸⁾
Avoid prone positioning for exercise with all levels of MSCC
Care should be taken when performing shoulder movements to end of range and /or with resisted arm exercise in patients with cervical or upper thoracic MSCC ^(4, 20, 52, 58, 59) . If any increase in pain or altered neurological symptoms occurs, the activity should be stopped.
Avoid overstretching of the wrist and finger flexors in C6 / 7 tetraplegics who require a tenodesis grip ^(59,61)
Care should be taken when performing hip / pelvic movements to end of range and straight leg raising in patients with low thoracic, lumbar or sacral MSCC ^(4, 20, 52, 58, 59) . If any increase in pain or altered neurological symptoms occurs, the activity should be stopped.
Care should be taken to preserve ankle dorsiflexion range of movement and to prevent drop foot contractures ^(37,58,59)

Respiratory Care

Physiotherapists should provide respiratory assessment and treatment as required to patients with MSCC within the preventative, restorative and supportive phases of care ^(19, 23, 24, 27). If necessary, pain management should be optimised prior to respiratory care. It may be appropriate to use these interventions in combination, dependent on problems presenting. Monitoring of pain and neurological symptoms throughout Physiotherapy treatments is advised ⁽³⁰⁾.

Interventions may include:

Secretion mobilisation and clearance

- Airway clearance techniques including Active Cycle of Breathing Techniques, Autogenic Drainage, Forced Expiratory Techniques, Postural drainage
- Manual assisted cough; Mechanical insufflator-exsufflator
- Abdominal binders
- Expiratory aids e.g. PEP, Flutter, Acapella
- Suctioning
- General exercise
- Breathlessness management ^(3, 19, 23, 26, 27, 28, 29, 30, 37)

Respiratory system support

- Oxygen Therapy; NIV
- Nebuliser & Inhaler Therapies
- Glossopharyngeal Breathing; Breath stacking; Incentive spirometry; Deep breathing exercises
- Abdominal binders
- Respiratory Muscle Training
- Positioning
- General exercise
- Exercise training
- Breathlessness management. ^(19,23,24,27,28,29,30,37)

Respiratory input during stable and exacerbation phases may necessitate different plans of care. Self-care of respiratory symptoms should be encouraged and a strong emphasis placed on educating the patient and carers in regard to respiratory symptoms and management. Where the use of home oxygen has been indicated, all equipment and devices should be managed as per individual Trust policy.

Prevention of contractures and/or spasticity control

Prevention of contractures and/or spasticity control may include:

Corrective positioning and splinting

Corrective positioning and regular change of limb position are critical aspects in maintaining joint ROM, preventing contractures and controlling spasticity⁽⁸⁷⁾

Patients with MSCC are at risk of developing upper and lower limb muscle contractures due to muscle weakness or occasionally spasticity.

Splints and serial casting may be considered for the elbows, wrists, hands, knees, ankles or feet to prevent or reduce contractures, prevent deformity, stabilize joints, maintain functional position and prevent overstretching of ligaments⁽²²⁾ Regular skin checks for pressure areas with splints and serial casting are necessary and modifications to the splint should be anticipated and provided as required⁽²²⁾.

Soft supportive foot splints or alternatively propping the feet to at least 90° in bed should be implemented to prevent a drop foot contracture in MSCC patients in bed^(34, 37, 58, 59)

Patients with ankle weakness or a “drop foot” may also require provision of an Ankle Foot Orthosis (AFO), or similar, for safe walking to prevent catching of the toes and trips, foot and ankle trauma and contractures.

It is important to monitor the range of movement (both active and passive), in light of the potential for further deterioration and modify advice / splinting accordingly.

Consideration should be given to positioning limbs out of spastic patterns where spasticity is evident, to reduce spasticity and prevent contractures of muscles and joints^(4, 20, 59, 81)

Physiotherapy stretching and exercises (see Physiotherapy exercises)

Bobath techniques, massage, rhythmic passive movements, active exercises and stretching techniques may be beneficial for reducing spasticity and preventing contractures however supportive research evidence is limited and often of low quality (20,58,59,81,88)

Weight bearing activities e.g. standing or weight bearing muscle stretches, may also decrease spasticity and prevent contractures (81)

Mixed and limited research evidence exists for physiotherapy stretching following a spinal cord injury (SCI), to increase ROM and prevent contractures with both positive evidence (50,89,90,91) and negative evidence (92,93).

Expert opinion and best practice guidelines recommend certain positions for stretching and prevention of contractures in patients who has sustained an SCI provided there are no contraindications. These guidelines can be applied to patients following a metastatic spinal cord compression:

- Tetraplegic Physiotherapy arm positioning stretches may be considered: See Appendix 7 (20,37,59)
- Frog leg positioning stretches may also be considered (59)
- Feet should be propped up to at least 90° to maintain ankle dorsiflexion and tendo-achilles length (37,59)

Muscle relaxants e.g. baclofen/botulinum toxin may be considered for spasticity control (4, 20, 59, 88)

Swelling/Deep Venous Thrombosis (DVT) Prevention and Management

DVT is a potential complication after spinal cord injury and alongside cancer and chemotherapy may result in haemostasis and/or increased blood viscosity. However, incidence can be reduced with prophylactic management (20, 39, 40). Strong evidence exists to support the use of graduated compression stockings (GCS) alone (94) and combined with low molecular weight heparin (LMWH) (39, 95, 96, 97) to reduce the incidence of DVT.

According to research and best practice, prophylactic GCS should be fitted and LMWH administered while MSCC patients are on bed rest and if/until mobility resumed, unless contraindicated ^(3, 4, 20, 37, 39, 40, 41, 53, 58). Contraindications to GCS include PVD, pressure ulcers and dermatological conditions ⁽³⁷⁾.

Exercises, passive movements, change of position, elevation and specialist lymphoedema input may also be provided to increase circulation and to reduce swelling and DVT incidence ^(4, 20, 37, 39, 53, 59)

Pressure Ulcer Prevention and Skincare

It is advised that the patient should be commenced on the local Trust pressure ulcer prevention and management pathway and that pressure ulcer risk assessment should be repeated regularly and as frequently as indicated by the individual's condition ⁽³⁴⁾

The skin should be inspected frequently for signs of redness in those individuals identified as being at risk of pressure ulceration ⁽³⁴⁾. Areas of special concern include the sacrum, coccyx, ischial tuberosities, trochanters, scapulae, occiput, heels, digits, nose and ears ⁽³⁴⁾. For the patient with MSCC who is no longer on bed rest and is mobile, family/carers should be encouraged to check the status of the skin at least once daily ⁽³⁾. The skin beneath GCS, bracing (e.g. cervical collar) or splints should also be checked daily or more frequently if necessary ⁽³⁷⁾.

The selection of an appropriate support surface, when in bed, should take into consideration pressure ulcer risk, skin integrity, sensation, the individual's level of mobility within the bed and comfort ⁽³⁴⁾

Shear forces increase at the sacrum, heels and ischial tuberosities when sitting in bed at an angle above 30°. These forces can be reduced by flexing the knees using the bed mechanism ^(34, 98) and the patient's knees should be always be flexed before the head of the bed is raised (if the patient is using a profiling bed) ⁽⁹⁹⁾. A pillow placed under the calves to elevate the heels may be considered so that the heels are free from the surface of the bed ⁽³⁴⁾. Heel protection devices may also be considered.

Those patients who sit out and are at risk of pressure ulcers - have restricted mobility, reduced sensation or postural needs; should be assessed by Occupational Therapy for an appropriate pressure-redistributing cushion. This assessment should be conducted in conjunction with seating, and as appropriate, wheelchair assessments ⁽³⁴⁾. (See Seating Assessment and Wheelchair Use)

During transfers, there can be increased risk of friction, shearing and injury due to the inadvertent bumping or striking of body surfaces on equipment. Care should be taken to prevent skin trauma and injury, through safe handling.

Attention should be paid to good skin hygiene and moisturising, and adequate nutrition and hydration ⁽²⁰⁾. Skin emollients should be used to hydrate dry skin, in order to reduce the risk of skin damage ⁽⁹⁸⁾

The skin should be protected from exposure to excessive moisture e.g. perspiration, urinary or faecal incontinence, wound or fistula drainage or vomit. Barrier creams and sprays can be useful in protecting moist skin from damage, especially from urine. However, it is best to manage incontinence so that the skin does not come into contact with urine e.g. through catheterisation. Care is required to ensure that the use of pads does not interfere with the pressure redistribution properties of any support surface. ^(34, 98)

Individuals with nutritional risks and pressure ulcer risk should be referred to a registered dietitian ^(34,100) and a tissue viability nurse for assessment and intervention as necessary ⁽³⁶⁾

Clothing should be loose, soft and free from buttons, metal studs and thick seams ⁽⁵⁹⁾. With regards to pressure ulcer risk, comfort may be the overriding and acceptable goal, even though it may be in conflict with best skin care practice ⁽³⁵⁾

Fatigue Management and Increased Exercise Tolerance

The goal of fatigue management in MSCC is palliation – i.e. to alleviate the effects of fatigue and maximise existing energy levels ⁽³¹⁾. Therapists should be competent to provide advice and information regarding general fatigue management strategies and should concentrate on patient goals, desired outcomes including promoting independence, participation in normal activities and aspects relating to quality of life ⁽¹⁰¹⁾. Management should include:

- Continuous assessment regarding severity and impact of fatigue ^(32,33)
- Education about fatigue should be offered to all patients and families ^(32,33)

Table 4: Fatigue levels and suggested relevant management strategies

Type of Fatigue	Suggested Management
<p>Mild fatigue (Score 0 -3)</p> <ul style="list-style-type: none"> - Minimal fatigue symptoms - Able to carry out Activities of Daily Living (ADLs) self-care, homemaking, work, leisure 	<ul style="list-style-type: none"> - Education/information re: fatigue - General management strategies including energy conservation techniques (ECT) - Encourage use of a fatigue diary ^(32,33)
<p>Moderate fatigue (Score 4-6)</p> <ul style="list-style-type: none"> - Symptoms present and cause moderate to high levels of distress - Decrease in daily physical activities, some impairment in physical functioning <p>Severe fatigue (Score 7-10)</p> <ul style="list-style-type: none"> - Significant fatigue on a daily basis, excessive need to sit or sleep, severe impairment of ADLs - Sudden onset of fatigue and/or shortness of breath at rest, rapid heart rate and/or blood loss 	<ul style="list-style-type: none"> - Include above and - Focused history - Contributory factors considered - Non-pharmacological interventions including energy conservation techniques ; physical activity advice; exercise tolerance/graded exercise programmes - Psychosocial interventions - Nutrition & Hydration advice - Sleep quality advice - Stress reduction strategies e.g. relaxation techniques - Complimentary therapies ^(32,33)

Sensory and proprioception re-education

Education on sensory and proprioceptive deficits and implications on function should be provided. Integration, use and exercise of the affected limb(s) should be encouraged where possible. Compensatory techniques and modification of the environment may be required. The need for increased safety awareness should be emphasised as necessary ⁽¹⁰²⁾

Cognitive Care

An acute episode of confusion may occur due to a number of factors (see Cognitive Factors). This can impact on cognitive functions such as memory, judgement, problem-solving and safety awareness. Family and carers may need to be alerted to the potential of this occurring and seek medical advice in this event.

The Occupational Therapist may use various approaches to help manage cognitive changes including:

- Reinforcing, strengthening or re-establishing previously learned patterns of behaviour
- Establishing new patterns of cognitive activity through compensatory cognitive mechanisms for impaired neurologic systems
- Establishing new patterns of activity through external compensatory mechanisms such as environmental structuring and support
- Enabling persons to adapt to their cognitive disability, even though it may not be possible to directly modify or compensate for cognitive impairment, in order to improve their overall level of functioning and QOL ^(103,104,105)

Psychological care

Patients and their families should be provided with the opportunity to discuss their concerns, emotions, distressing issues, mood and interests, anxiety, adjustment to illness and treatment, strengths and existing support ^(106,107)

Screening and the identification of the types of problems that cause the most distress can indicate which type of professional referral the patient should receive or which type of intervention may be most beneficial ⁽⁵⁸⁾ Patients should be informed about the range of support services available and how to access these ^(3, 20, 109). A

local directory of organisations and community resources that provide support and information can be found at: <http://survivorship.cancerni.net> ⁽¹¹⁰⁾. Onward referral will be dependent on patient consent.

Cognitive Behavioural Therapy, which can include cognitive restructuring, increasing the person's access and willingness to engage in rewarding activities, various forms of relaxation training, problem solving strategies, as well as assertiveness and coping skills training, is moderately effective in improving symptoms of depression, coping and adjustment ⁽¹¹¹⁾

Realistic goal setting as part of the rehabilitation process to maximise independence and control should be negotiated and implemented.

Adjustment to disability

Patients with MSCC have to live with the psychological, physical and emotional effects of advanced cancer as well as the consequences of a disability and the impact this has on their day to day lives ⁽¹¹²⁾.

In the early stages, patients may be uncertain and unrealistic of their abilities and the potential impact their disability has on their lives. An opportunity should be given to explore and set goals, along with members of the multi-disciplinary team ^(3, 20,112). While patients may describe goals and plans that seem overly optimistic and impracticable, other goals may be feasible and grounded. Rather than directly contradict unrealistic goals, reasonable and achievable goals should be encouraged and agreed ⁽¹¹²⁾

Involvement and education of patient/ family/carer

For people with advanced illness 'taking charge' can become a priority for them ⁽¹¹⁴⁾. Being able to be as involved in your own care, with the right to exercise choice and control, correlates to preserving dignity and maintaining normality ⁽¹¹⁵⁾.

Supported self-management has been advocated as a method of enabling patients to play an active part in their own health and wellbeing ⁽¹¹⁶⁾. It aims to help put the person and their family back in charge ⁽⁸⁰⁾.

In practice, self-management can come in many forms. Professional assessments should routinely ask 'how much do you understand about your condition?' to help understand patients (and their families') information needs ⁽⁸⁰⁾. Patients and their families should be actively provided with information to better understand their condition, dependant on their needs and wishes ⁽⁸⁰⁾.

Patient/client information and education about Metastatic Spinal Cord Compression is an important component of care ⁽¹¹⁷⁾. Late detection is a common occurrence in patients with MSCC and many present with advanced symptoms ⁽¹¹⁸⁾. Information being provided to patients provides a key role in early detection⁴ and therefore better outcomes for the patient ⁽¹¹⁹⁾.It is important also in the event of recurrence of MSCC to access prompt management.

Patient, family and caregiver education should be provided as appropriate in the following areas:

- Reporting of initial occurrence of signs and symptoms, increased or /re occurrence of signs and symptoms e.g. pain or neurological symptoms or decreasing mobility.
- Respiratory Care
- Skin care and pressure ulcer prevention
- Handling and transfer methods
- Fitting and use of any orthosis and bracing with advice on hygiene/changing of liners and skin checks
- Stretches and exercises
- Application and use of compression stockings (where indicated)
- Personal care activities
- Safe use of prescribed equipment
- Walking and walking aids

- Stair techniques
- Non Pharmacological Symptom management to include
 - Relaxation Techniques
 - Fatigue Management, including energy conservation techniques/ lifestyle management
 - Breathlessness Management
 - Mindfulness

The methods of delivery of patient /family/ carer education and involvement can vary depending on the environment in which the patient is receiving their care, and the individual's circumstances or needs ⁽¹²⁰⁾. Options include formal group education, use of IT to interact with patients/family/carers, as well as informal one to one education or advice when visiting patients in their own home.

All patients with cancer, known bone metastases including those previously diagnosed with MSCC and those considered at high risk of developing bone metastases, should be given information on what to look out for and whom to contact for urgent advice ^(1,114). Although there may be reluctance to provide prophylactic information, this approach has been shown to have been advocated by patients who have developed MSCC and did not have the knowledge or information regarding warning signs ⁽¹¹⁶⁾.

If patients are helped to understand their situation they are able to make decisions regarding their health and their care. Care should be taken in all cases to deliver information in a sensitive manner, in order to highlight the issues but to minimise additional anxiety ⁽¹¹⁷⁾.

Northern Ireland Cancer Network (NICaN) has produced a leaflet ⁽¹⁶⁾ to highlight the signs and symptoms of MSCC to patients and their family. This leaflet will be given to patients at Oncology clinics when radiology has confirmed the patient is at high risk of developing MSCC.

Education and advice given to patients and their carers or family should be appropriate to their level of need, depending on the stage of their illness. As with the goal of overall rehabilitative palliative care, the aim should be to improve function where the patient has capacity, maintain function where the effects of illness and its treatment threaten decline, or ease the transition towards functional decline when deterioration is inevitable ⁽¹²¹⁾.

Where there is a potential for palliative rehabilitation to be offered outside the home setting, this should be discussed with the patient and their consent gained for onward referral. Availability of this option varies within Trusts across the Region.

End of Life Considerations

End of Life Considerations

Survival times for adults with MSCC vary from just a few weeks to over a decade, depending on their primary cancer and the presence of visceral metastases. Most have a poor prognosis of only a few months.⁽¹²⁶⁾ MSCC is closely associated with the end of life because of its high incidence in the late stages of advanced malignancy.

The Occupational Therapists and Physiotherapists, work as part of a multi-disciplinary team, delivering interventions which optimise patient's physical and psychological functioning, whilst supporting patients and their families as they cope with the effects of advancing disease.

When end of life (last few days/weeks) has been recognised and is approaching, the patient's needs should be reviewed, reflecting the change in their condition, and goals of intervention modified appropriately by the therapists involved.

It is essential to have a sensitive approach when acknowledging this and discussing the benefit of therapeutic intervention. It may not be feasible to continue active rehabilitation and comfort will be the overriding and acceptable goal.

At this stage the emphasis shifts to supportive care, which involves preparing the patient and the family for the inevitable decline that occurs at the end of life.¹²⁴

It is important to acknowledge the role of and need for peer support and reflective practice for those staff working with this particular patient group.

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Appendix 1 - Search Terms used in the Electronic Search:

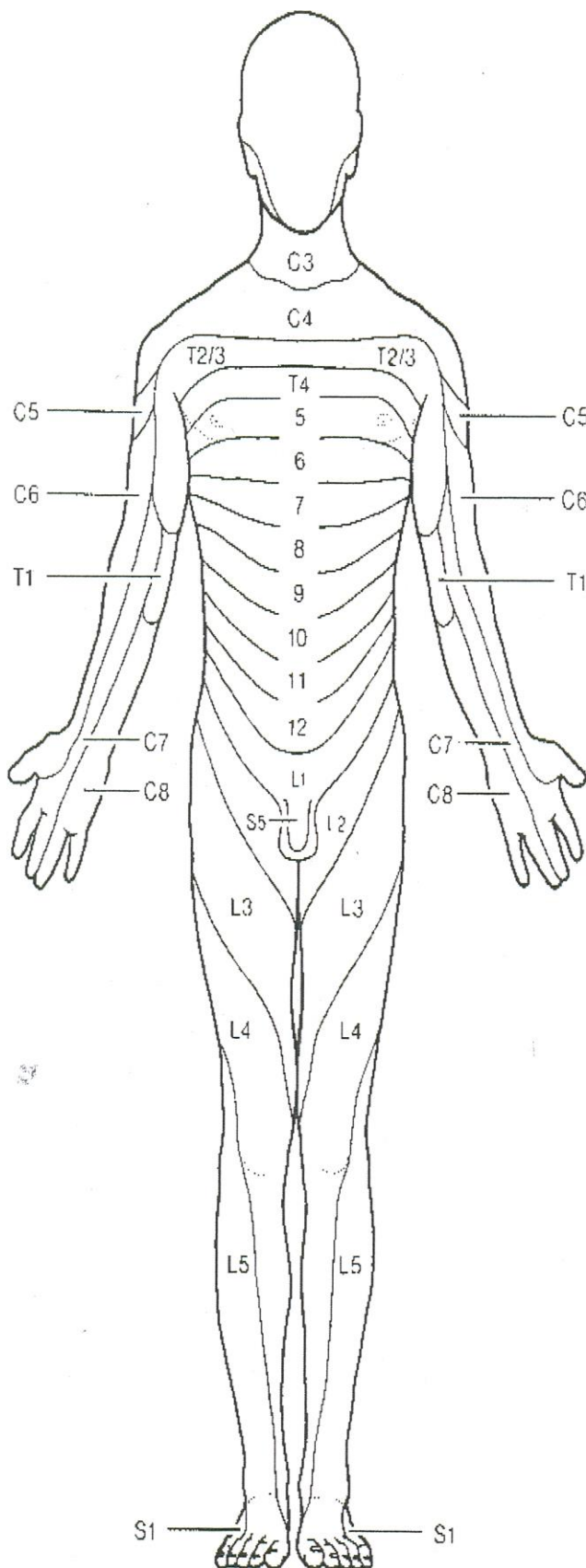
Spinal cord and rehabilitation/therapy/physiotherapy/occupational therapy
Spinal cord cancer and therapy
Spinal cord and assessment and rehabilitation
Metastatic spinal cord compression
Spinal cord and patient positioning/positioning
Spinal cord and moving and handling/manual handling
Spinal cord and bracing/spinal bracing
Spinal cord and cervical collars/cervical collars
Spinal cord and orthoses/and ankle foot orthoses (AFO)/spinal cord and AFO/AFO
Spinal cord and immobilisation/spinal cord and stabilisation/spinal cord and mobilisation
Spinal cord and passive movements
Spinal cord and stretching
Passive movements/range of movement (ROM)/contractures
Stretching and prevention of contractures
Physiotherapy and spasticity
Spinal cord and exercise/and bed exercise/and ROM exercise
Spinal cord and exercise and cancer/cancer and exercise
Spinal cord and chest physiotherapy/respiratory physiotherapy/breathlessness
Assisted cough
Spinal cord and seating/wheelchairs
Spinal cord and Activities of Daily Living
Spinal cord and functional assessment
Spinal cord and assistive technology/environmental control units
Cancer related fatigue

Cancer and cognitive assessment / therapy
Cancer and pain management
Cancer and relaxation
Pressure ulcer/guidelines
Spinal cord and psychological adjustment
Spinal cord and carers needs
Spinal cord and rehabilitation/home based therapy/physiotherapy/occupational therapy
Spinal cord cancer and home based therapy
Spinal cord and gait rehabilitation/home based
Spinal cord and patient positioning/positioning in the home setting
Spinal cord and seating/wheelchairs in the community
Spinal cord and activities of daily living in the home setting
Cancer related fatigue/metastatic spinal cord compression/home setting
Spinal cord/Non pharmacological pain management
Spinal cord/seating/pressure relief
Spinal cord neoplasm/rehabilitation/homebased
Supportive care/end of life in the home setting

Appendix 2 - Abbreviations

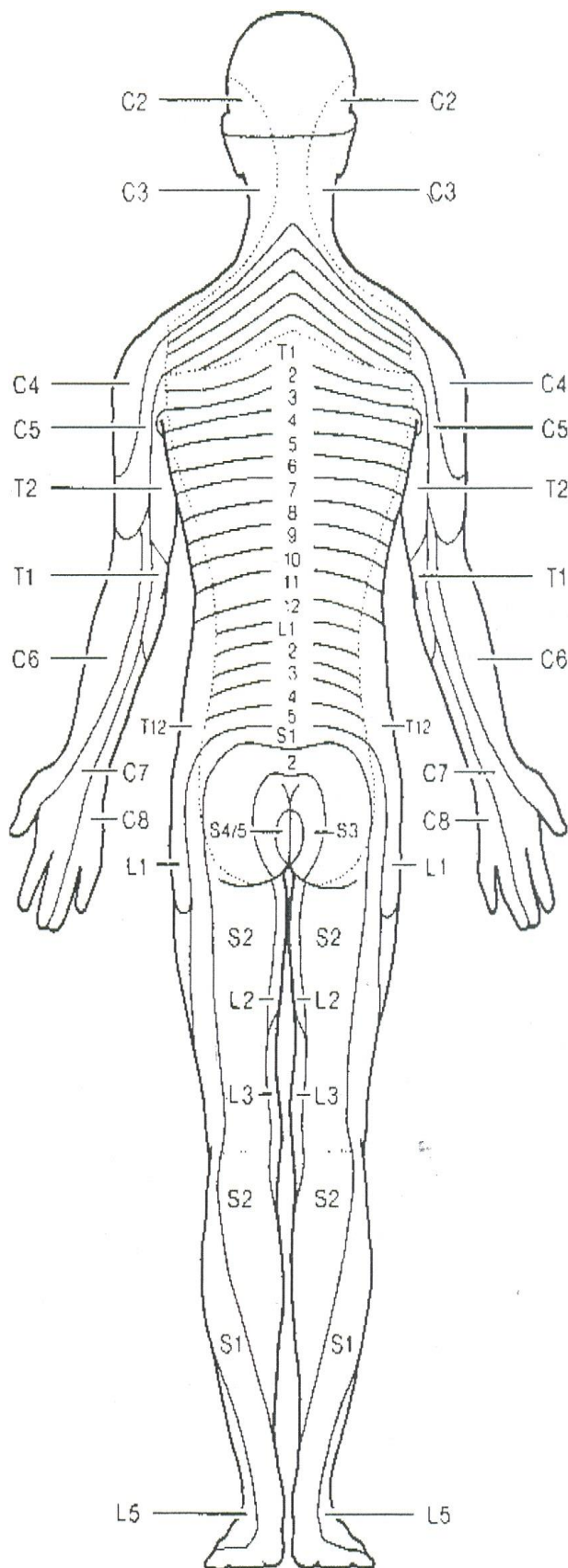
ABGs	Arterial blood gases
ADLs	Activities of daily living
AFO	Ankle foot orthoses
AHP	Allied health professional
BP	Blood pressure
BSI	Brief symptom inventory
COPD	Chronic obstructive airways disease
DR	Delta rollator
DVT	Deep venous thrombus
FES	Functional electrical stimulation
FEV1	Forced expiratory volume in 1 sec
GCS	Graduated compression stockings
GP	General practitioner
HADS	Hospital anxiety and depression score
HCP	Health care professional
HR	Heart rate
IADL	Instrumental activities of daily living
IPPB	Intermittent positive pressure breathing
IPPV	Invasive positive pressure ventilation
LMWH	Low molecular weight heparin
MRI	Magnetic resonance imaging
MSCC	Metastatic spinal cord compression
NIPPV	Non-invasive positive pressure ventilation
O ₂	Oxygen
PADL	Personal activities of daily living
PDI	Psychological distress inventory
PVD	Peripheral vascular disease
QOL	Quality of life
ROM	Range of movement
RR	Respiratory rate
SAO ₂	Oxygen saturation
SCI	Spinal cord injury
SOB	Shortness of breath
TENS	Transcutaneous electrical nerve stimulation
VC	Vital capacity
ZF	Zimmer frame
ZR	Zimmer rollator

Appendix 3: Dermatome Chart : Sensory Levels



C2-C3	Neck
C4	Upper shoulder Upper anterior chest
C5	Lateral shoulder
C6	Radial forearm Thumb Index finger
C7	Middle finger Median strip of hand Back of hand
C8	Ring and little Finger Ulnar forearm
T1-T2	Proximal medial arm Axilla
T2-T-12	-
T4	Nipple line
T7	Lower costal margin
T10	Umbilicus
T12	Groin
L1-L2	Proximal anterior thigh
L3	Anterior knee
L4	Anterior lower leg
L5	Great toe Medial dorsum of foot
S1	Lateral border of foot Sole Along Achilles tendon
S2	Proximal posterior thigh
S3, S4, S5	Genitals and saddle area

Appendix 4a: Myotome Chart – Motor Levels



MOTOR LEVELS

Neck muscles

Diaphragm (Phrenic Nerve)
Trapezius

Deltoid (C4) Biceps (C4-5)

Extensor carpi radialis

Triceps (C7)
Extensor digitorum

Flexor digitorum

Hand intrinsics (T2)

Intercostals

Abdominals (T7-L2)

Ileo-psoas (L2)
Adductors (L2)

Quadriceps (L3)

Medial hamstrings
Anterior tibialis

Lateral hamstrings
Posterior tibialis
Peroneals

Extensor digitorum
Extensor hallucis (L5)
Gastrocnemius (S1)
Soleus (S1)

Anal/Bulbocavernosus reflexes
(S2, S3, S4)

Bladder Lower Bowel

Appendix 4b: Oxford Classification of Muscle Power

Numerals	Letters	Description
Against gravity tests		The patient is able to actively move through:
5	N (normal)	The full available ROM against gravity and against maximal resistance
4	G (good)	The full available ROM against gravity and against moderate resistance
4-	G-	Greater than one half the available ROM against gravity and against moderate resistance
3+	F+	Less than one half of the available ROM against gravity and against moderate resistance
3	F (fair)	The full available ROM against gravity
3-	F-	Greater than one half the available ROM against gravity
2+	P+	Less than one half the available ROM against gravity
Gravity eliminated tests		The patient is able to actively move through:
2	P (poor)	The full available ROM gravity eliminated
2-	P-	Greater than one half the available ROM gravity eliminated
1+	T+	Less than one half the available ROM gravity eliminated
1	T (trace)	None of the available ROM gravity eliminated and there is a palpable or observable flicker of a muscle contraction
0	0 (zero)	None of the available ROM gravity eliminated and there is not palpable or observable muscle contraction

Appendix 5: The Modified Ashworth Scale of Spasticity

The Ashworth Scale		
Score	Ashworth Scale (1964)	Modified Ashworth Scale Bohannon & Smyth
0 (0)	No increase in tone	No increase in muscle tone
1 (1)	Slight increase in tone giving a catch when the limb was moved in flexion or extension	Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the range of motion when the affected part(s) is moved in flexion or extension
1+ (2)		Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout the remainder (less than half) of the ROM (range of movement)
2 (3)	More marked increase in tone but limb easily flexed	More marked increase in muscle tone through most of the ROM, but affected part(s) easily moved
3 (4)	Considerable increase in tone - passive movement difficult	Considerable increase in muscle tone passive movement difficult
4 (5)	Limb rigid in flexion or extension	Affected part(s) rigid in flexion or extension

Appendix 6 – The Spinal Stability and Mobility Recommendations Proforma

Metastatic Spinal Cord Compression Patient Management Information



For patients with a known history of cancer contact the oncology registrar 028 29032924-1 in the Cancer Centre.

For patients with no known history of cancer, for a surgical opinion phone Fracture Clinic 028 90632925 / 028 90633133 and ask for front of house **SHO**. Complete as much of form as possible.

Date: <input style="width: 100%;" type="text"/>	Clinical oncology oncologist: <input style="width: 100%;" type="text"/>
Patient Details Health and Care Number: <input style="width: 100%;" type="text"/> Surname: <input style="width: 100%;" type="text"/> Forename: <input style="width: 100%;" type="text"/> Date of Birth: <input style="width: 100%;" type="text"/> Address: <input style="width: 100%;" type="text"/> Postcode: <input style="width: 100%;" type="text"/> Telephone: <input style="width: 100%;" type="text"/> Location: <input style="width: 100%;" type="text"/>	Relevant Medical History 1. <input style="width: 100%; height: 40px;" type="text"/> 2. <input style="width: 100%; height: 40px;" type="text"/> Anticoagulation <input type="radio"/> yes <input type="radio"/> no Bleeding Tendency <input type="radio"/> yes <input type="radio"/> no Immunosuppression <input type="radio"/> yes <input type="radio"/> no Previous Radiotherapy to spine? <input type="radio"/> yes <input type="radio"/> no Site/Dose: <input style="width: 100%; height: 30px;" type="text"/> MRI Summary (if available): <input style="width: 100%; height: 30px;" type="text"/> Radiology system accessible from: <input style="width: 100%;" type="text"/>
Referrer's Details Name: <input style="width: 100%;" type="text"/> Profession: <input style="width: 100%;" type="text"/> Land line: <input style="width: 100%;" type="text"/> Mobile: <input style="width: 20%; border: 1px solid black;" type="text"/> Bleep: <input style="width: 20%; border: 1px solid black;" type="text"/> Location: <input style="width: 100%;" type="text"/>	Patient Understanding Diagnosis discussed with patient? <input type="radio"/> yes <input type="radio"/> no Does patient wish to consider surgery? <input type="radio"/> yes <input type="radio"/> no Has there been an end of life discussion with the patient? <input type="radio"/> yes <input type="radio"/> no Estimated Life Expectancy >3 months <input type="radio"/> yes <input type="radio"/> no <input type="radio"/> Unknown
Primary: <input style="width: 100%; height: 40px;" type="text"/> Secondary: <input style="width: 100%; height: 40px;" type="text"/>	Oncology/Haematology Consultant Decision <input type="checkbox"/> 1. Spinal surgery advice <input type="checkbox"/> 2. Radiotherapy 5 fractions <input type="checkbox"/> 3. Radiotherapy 1 fraction <input type="checkbox"/> 4. Best supportive care (BSC)
Presentation: <input style="width: 100%;" type="text"/> Duration of symptoms: <input style="width: 100%;" type="text"/>	Surgical advice (if appropriate) Time of call: <input style="width: 100%;" type="text"/> Time of surgical decision: <input style="width: 100%;" type="text"/> Surgery recommended? <input type="radio"/> yes <input type="radio"/> no Steroid advice <input type="radio"/> yes <input type="radio"/> no <input type="radio"/> n/a
Neurological History pain? <input type="radio"/> yes <input type="radio"/> no Location: <input style="width: 100%;" type="text"/> Type: <input type="checkbox"/> Mechanical <input type="checkbox"/> Postural <input type="checkbox"/> non-Specific Pattern: <input type="checkbox"/> Nocturnal <input type="checkbox"/> Diurnal <input type="checkbox"/> Constant Neurological Status Walking status <input type="checkbox"/> Normal <input type="checkbox"/> Unsteady <input type="checkbox"/> Non-ambulant Incontinence: Urinary <input type="radio"/> yes <input type="radio"/> no Faecal <input type="radio"/> yes <input type="radio"/> no Sensory Level: <input type="radio"/> yes <input type="radio"/> no If yes, level: <input style="width: 100%;" type="text"/> Motor Deficit: lowest grade <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 Muscle Group: <input style="width: 100%;" type="text"/> Duration: <input style="width: 100%;" type="text"/> Able to lift leg off bed? Right: <input type="radio"/> yes <input type="radio"/> no Left: <input type="radio"/> yes <input type="radio"/> no	Additional Information Date: <input type="checkbox"/> Hb <input type="checkbox"/> WCC <input type="checkbox"/> ANC <input type="checkbox"/> Plt Resuscitation Status: <input style="width: 100%;" type="text"/> DNAR Date: <input style="width: 100%;" type="text"/> DNAR/Advance Directive: <input type="radio"/> yes <input type="radio"/> no Outcome summary: <input style="width: 100%; height: 40px;" type="text"/>

Identifying Spinal Instability

Spinal instability is thought to account for pain in approximately 10% of patients with vertebral metastases and is characterized clinically by severe pain at the site of the lesion on attempted movement. Instability may be present if the following are present:

1. Severe pain at site of lesion, increasing on movement.
2. Worsening neurology (increasing pins and needles and/or weakness)
3. Involved vertebral bodies have collapsed to less than 50% of their original height.
4. The odontoid process has been destroyed, leading to possible atlanto-axial subluxation.

Patients may complain of severe pain when turning over in bed or attempting to get up especially when there is spinal instability at lower spinal levels. Such a patient may be unwilling to move the affected part and exhibits tenderness to palpation or percussion over the area.

Patients with odontoid fractures or atlanto-occipital dislocations may hold their neck stiffly and sometimes in a slightly awkward position. They may refuse to move it actively or allow themselves to be moved passively. Occasionally numbness is felt in the tongue where there is compression of afferent nerves which lead to the second cervical root. The subluxed vertebral column may compress the cord causing quadriplegia and respiratory distress.

“Clinical features of pain and neurology are the best indicators of instability”

Moving and Handling

Moving and handling recommendations need to be made for each patient with MSOC. Alongside radiological findings consider the following moving and handling options and then **select one option** for the patient's care team. For patients at end of life, be aware of the implications of recommendations on quality of life.

Recommendation for patients (tick only one)

- Bed rest & log roll**
If patient has increasing pain and worsening neurology on movement consider recommending bed rest and log roll. Review recommendations daily.
- Monitored graduated sit-up and mobilise as pain and neurology allows**
If patient has manageable pain, stable neurology and walking prior to diagnosis consider recommending graduated sit-up and progress to mobilise as pain and neurology allows. Bracing may also be appropriate - liaise with physiotherapists.
- Mobilise as pain and neurology allows**
If patient has minimal pain, neurology and is independently mobile consider recommending mobilise as pain and neurology allows.

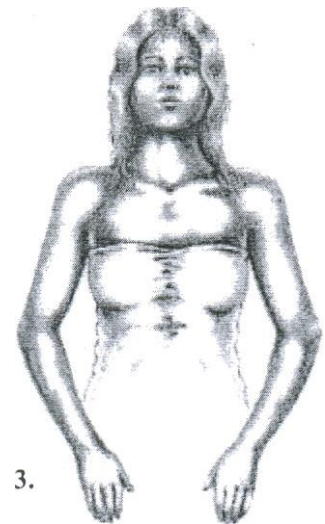
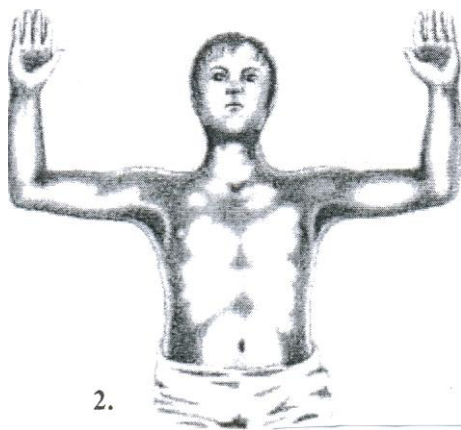
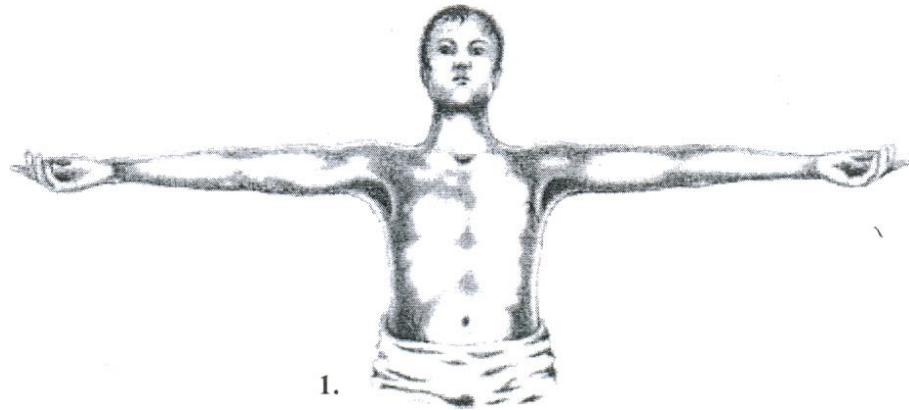
[Email to RMH](#)

[Email to Cancer Centre](#)

[Print Form](#)

Appendix 7: Tetraplegic Arm Positioning

Pictures 1-3 illustrate appropriate arm positioning for the prevention of upper limb contractions in tetraplegic patients.



Appendix 8: Functional Independence ⁽¹²⁵⁾

Segmental level	Personal independence	Wheelchair management	Transfers	Gait
C4	Type, turn pages, use telephone and computer with mouthstick			
C5	Type Feed	Manipulate brake Push on the flat		
C6	Drink Wash, shave, brush hair Dress upper half Sit up/lie down in bed Write	Remove armrests/footplates Push on sloping ground Turn chair	Chair ↔ bed Chair ↔ car ?with sliding board	
C7	Turn in bed Dress lower half Skin care	Pick up objects from floor Wheel over uneven ground 'Bounce' over small elevations	Chair ↔ toilet chair Chair ↔ bath ?chair ↔ bath	Stand in frame
C8	Bladder and bowel care	Negotiate kerbs	Chair ↔ bath	Stand in frame
T1-T5		Balance on rear wheels Pull wheelchair into car	Chair ↔ floor	Stand in frame Swing-to in bars
T6-T9			Chair ↔ crutches	Swing-to on crutches or rolator ?Stairs
T10- L1				All three gaits on crutches Stairs Car ↔ crutches Floor ↔ crutches

Appendix 9: Useful Resources

- <https://itunes.apple.com/gb/app/nerve-whiz/id380714187?mt=8>
- <https://itunes.apple.com/gb/app/dermatomes/id371093098?mt=8>
- <http://www.friendsofthecancercentre.com/news/2016/new-information-video-launched-to-help-radiotherapy-patients/>
- http://www.cancerni.net/sites/default/files/documents/NICaN%20Acute%20Oncology%20Clinical%20Guidelines_v1%20.9.pdf
- <https://www.nidirect.gov.uk/information-and-services/motoring.../blue-badge-scheme>
- Horizon Microguide app (for Acute Oncology Services Northern Ireland - available for Apple and Android devices)

Appendix 10: Key Steps In the Development of the Guideline



1. Establish a clearly defined remit.
2. The nominated Chair appoints a Guideline Development Group (GDG).
3. Each member of the GDG receives GAIN information on guideline development and quality appraisal of clinical guidelines.
4. The group sets the key questions.
5. Organisational and financial barriers to the application of recommendations of a guideline need to be discussed and addressed.
6. Members of the group then conduct systematic review searches, each member having responsibility for addressing a specific question.
7. The results of the searches are presented to the GDG and further searches may be commissioned.
8. Evidence tables are compiled for each of the key questions.
9. A draft guideline paper is submitted to GAIN based on the evidence search and evidence table check list.
10. This is circulated by GAIN to a large group of professionals with expertise in the area.
11. The results of the consultation process are forwarded to the GDG.
12. The GDG prepares a second draft of the guideline which may take account of the consultation process. The GDG also considers further key questions which may require additional searches.
13. The GDG present the second draft of the guideline to GAIN.
14. This is subject to a more limited consultation process of peer review.
15. The GDG then produces the final version of the guideline.
16. The guideline is launched at a regional meeting.
17. The GDG is reconvened by the Chairman after 2-3 years as part of the guideline review policy.

Appendix 11: Project Team

Name	Job Title	Organisation
Chairpersons		
Kathryn Carson	Macmillan Community Specialist Palliative Care Physiotherapist	South Eastern HSC Trust
Yvonne Smyth	Macmillan Community Specialist Palliative Care Occupational Therapist	Belfast HSC Trust
Project Team Members		
Bronagh Lynch	Macmillan Community Specialist Palliative Care Occupational Therapist	South Eastern HSC Trust
Carolyn Murdock	Macmillan Community Specialist Palliative Care Occupational Therapist	South Eastern HSC Trust
Kelly McCartney	Community Specialist Palliative Care Occupational Therapist	Southern HSC Trust
Lesley McCorry	Community Specialist Palliative Care Physiotherapist	Southern HSC Trust
Linda Willis	Community Specialist Palliative Care Physiotherapist	Southern HSC Trust
Nicola Porter	GAIN Manager	RQIA
Clodagh O'Brien	MSCC Regional Project Manager (2012-2014)	NICaN
Deborah Kerr	Macmillan Service Improvement Lead – Oncology (2014)	NICaN
Peer Reviewers		
Emma Hicks	Macmillan Clinical Specialist Occupational Therapist	Shrewsbury and Telford Hospitals NHS Trust
Shona Underwood	Macmillan Clinical Specialist Physiotherapist	Shrewsbury and Telford Hospitals NHS Trust



The Regulation and
Quality Improvement
Authority

The Regulation and Quality Improvement Authority
9th Floor
Riverside Tower
5 Lanyon Place
BELFAST
BT1 3BT

Tel 028 9051 7500

Fax 028 9051 7501

Email info@rqia.org.uk

Web www.rqia.org.uk

 [@RQIANews](https://twitter.com/RQIANews)