Acute Oncology Group
Hull University Teaching Hospitals NHS Trust
Queen's Centre

Malignant Spinal Cord Compression (MSCC)

Clinical Advisor Coordinator

Induction Training 2019

Version Control

This is a controlled document please destroy all previous versions on receipt of a new version.

Version	Date Issued	Review Date	Brief Summary of Change	Owner's Name
1.0	March 2012	March 2014	First Draft / NEYHCA branding and formatting	MSCC Group / AOCEG
1.0a	January 2014	March 2015	Pathway revised and New referral form added	MSCC Group / AOCEG
1.1	January 2016	January 2018	Update document to HEY	MSCC Group
2.0	May 2019	May 2021	Revise and Update	AOG

For the latest version of these guidelines please see the NEYHCA (Cancer) website
Please press control and click on the link below:

http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/mscc.htm

Signature Sheet

MSCC Clinical Advisor Induction Training 2012

These guidelines have been agreed by:

Title	Name	Date Agreed
Chair of the MSCC Group	Dr Nabil El-Mahdawi	16.1.16
Chair of the MSCC Group	Dr Nabil El-Mahdawi	29.3.12
Chair of the Acute Oncology CEG	Dr Lorcan O Toole	29.3.12
Chair, NEYHCA Board / NEYHCA Cancer Management Group	Mrs Allison Cooke	9.5.12
The MSCC Group have agreed these guidelines		29.3.12

Contents

1. MSCC Induction Training

(This is also available as part of the MSCC Clinical Advisors Specification document)

Background

Malignant Spinal Cord Compression (MSCC) includes compression of the spinal cord. MSCC is a major cause of morbidity and is believed to occur 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 (3, 4) 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.

The Need for an Educational Package

Early diagnosis of MSCC whilst the patient is still ambulant is crucial in optimising patient outcomes. 9 Studies carried out in the United Kingdom (UK) over the last 10 years have identified several areas where increased awareness of this condition and specific aspects of treatment and rehabilitation could be improved. (10, 11, 12). The main issues identified were:

- Unacceptable delays in diagnosis and referral are common.
- Clinicians failed to consider a diagnosis of spinal cord compression resulting in delayed investigation and referral.
- There is a lack of formal referral procedures for patients with MSCC.

Aetiology of MSCC

The spinal column is the most common site of bony metastases with the thoracic spine being most frequently affected (70%), followed by lumbosacral (20%) and cervical (10%). Extradural compression of the spinal cord occurs due to tumour expansion into the epidural space, usually from dissemination of malignant cells to the vertebral bodies or surrounding tissues via the vascular circulation. Direct extension from an intra-abdominal or intra-thoracic primary adjacent to it or a primary malignancy arising in the vertebral body can also occur. Intradural spinal cord neoplasms (intramedullary and extramedullary) or metastases (intramedullary) can also present with symptoms of spinal cord compression. MSCC can be the presenting manifestation of a cancer or can be the sole site of recurrence. It is however, more common for it to occur where there is widely disseminated disease. Most patients will die as a result of their underlying cancer within a year of the diagnosis of spinal cord compression; however, patients with more favourable prognostic factors can survive beyond two years.

Key Signs and Symptoms

Remember: Taking to bed or needing a catheter, even in the absence of pain, should raise the possibility of MSCC.

Pain

Spinal pain must be treated as significant and should not be assumed to be degenerative disc disease. Radicular pain in a patient with cancer is a major cause of concern.

Motor deficits

Specific muscle weakness may emerge initially in the legs regardless of the level of compression. Compression of the lower cervical and upper thoracic nerve roots can present with upper limb weakness. The patient may complain of ‘heavy’ or ‘stiff’ limbs causing, for example, difficulty climbing stairs.

Sensory deficits

Paraesthesia and loss of sensation may develop progressing upwards from the toes in a stocking-like fashion eventually reaching the level of the lesion but is poorly localized to the site of the lesion. The patient may experience altered sensation to touch, pain and temperature.

Autonomic dysfunction (usually late presenting symptoms)

Sphincter disturbances can increase the tendency to constipation and/or urinary retention and this can progress to double incontinence.

Referral pathways

It has already been stated that patients with actual or potential MSCC may present in a variety of settings to any health care professional. The individual’s presenting signs and

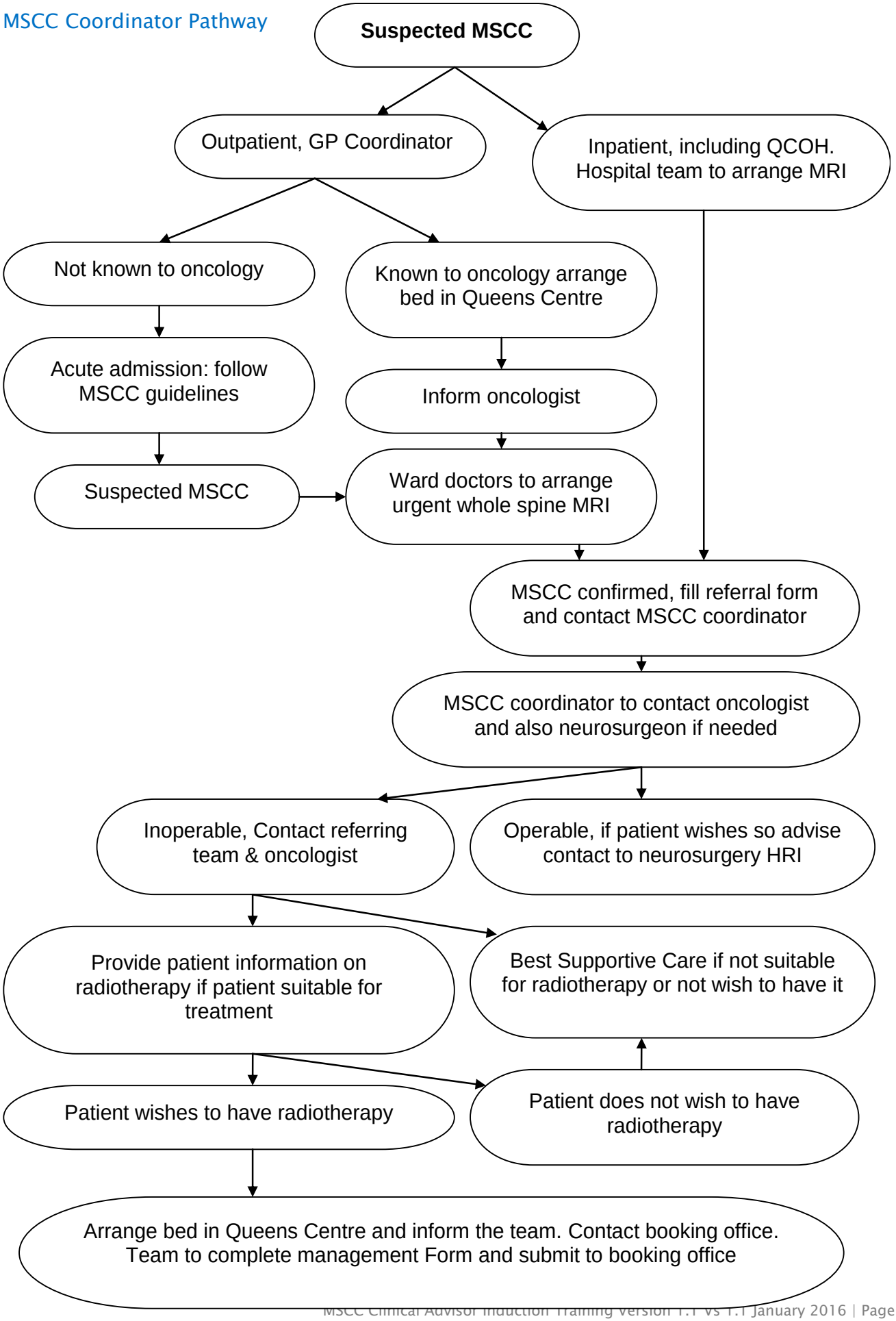
symptoms and general physical condition will influence the likely referral and treatment pathway. Please see the flow chart pathway in regard to the MSCC coordinators.

Management pathway

Clinical assessment and examination of a patient with suspected spinal cord compression includes identification of risk factors, symptom evaluation of pain, sensory and motor function, and bowel and bladder function.

- To ensure patient on steroids (Dexamethasone – 16 milligram/day (mg/d)).
- Suggest patient lies flat and advice on that they will require to maintain this position unless was advised by the spinal surgery team that the spine is stable.
- An emergency two-person ambulance with stretcher should be requested, to enable transfer of the patient from home to hospital.
- Admit direct to local hospital (avoiding Accident and Emergency, if possible).
- An urgent Magnetic Resonance Imaging (MRI) scan should be organised locally within 24hours. CT scan is an acceptable alternative if urgent MRI is not possible.
- If the individual is a hospice inpatient at the time of initial suspicion of MSCC, it would be preferable if an urgent local MRI could be arranged, rather than the patient having to be transferred as an in-patient to the local hospital.
- A Referral form must be completed and coordinator to facilitate telephone discussion with the on-call Oncologist and / or spinal surgery oncall is advised once clinical and radiological assessment has been performed.
- Ensure patient information has been handed to the patient and patient aware of the diagnosis and agreeing on the management plan before perusing into it.

MSCC Coordinator Pathway



Other points to consider

- pain and symptom management
- emotional/psychological support
- the need to consider spiritual needs and care
- family support
- rehabilitation/maximising potential
- discharge planning
- Assessment for hospice admission.

Specialist palliative care

Referral to the Specialist Palliative Care Service may be appropriate at any stage, from suspicion of MSCC, through diagnosis, treatment and rehabilitation to end of life care. It is particularly important when the issues are complex and are not able to be managed locally or when a multidisciplinary team approach to care has not been available but is required.

Rehabilitation and multi-professional referral

Rehabilitation should commence on diagnosis, encompassing the skills of various healthcare professions as appropriate.
Referrals should be considered to the following multi-professional staff:

- Physiotherapist (within 24 hours of admission)
- Occupational Therapist (within 24 hours of admission)
- Social Worker (when needed)
- Other where relevant (Dietician, Speech and Language Therapist, Clinical Psychologist or Counsellor and Hospital Chaplain)

Metastatic Spinal Cord Compression and timing of mobilisation – Initial Presentation

- Assume spine unstable until MDT decision made regarding stability.
- Advise flat bed rest, one pillow with neutral spine alignment until confirmation of spinal stability.
- Stabilisation with a hard collar for patients with suspected cervical cord compression. (MSCC coordinators trained to fit collars). Spinal brace may be indicated for thoracic or lumbar lesions (liaise with consultant and neurosurgeons)
- Patient must be log rolled and use slipper pan and bottle/urinary catheter, cot sides in place
- Correct intervention for pressure relief
- Above knee TEDS to prevent thrombosis.

Management pathway must be clearly documented and communicated to the team

Audit

Retrospective audit of clinical practice shows wide variation in the timing of, and methods used to mobilise patients diagnosed with MSCC during treatment. In the past mobilisation has usually only been started only after radiotherapy or spinal stabilisation, or following an arbitrary period of bed rest. However there is no research evidence to support any of these approaches. NICE recommends that a decision about spinal stability has to be made by the MDT, ideally including surgeon, radiologist, oncologist and physiotherapist and documented in the medical record.

Indicators of spinal instability

Most reliable indicators of spinal instability are radiological findings (MRI) and clinical features such as mechanical pain and changing neurological features. Spinal instability, often with subluxation, can result in progressive kyphosis with extrusion of bone and disc into the spinal canal. It is characterised clinically by severe pain at the site of the lesion on attempted movement.

Instability is likely to be present if any of the following are present:

- Severe pain at site of lesion, increasing on movement
- The tumour involves two or more adjacent vertebral bodies
- Both anterior and posterior elements at the same level are involved
- Involved vertebral bodies have collapsed to less than 50% of their original height
- The odontoid process has been destroyed leading to possible atlanto-axial subluxation *(WOSCAN, West Of Scotland Cancer Network Guidelines for malignant spinal cord compression, 2007)*

Stable spine

Once the spine is confirmed as stable, gentle mobilisation should be commenced as soon as possible, bearing in mind that this may be before, during or after definitive treatment. When pain is well controlled, gradual sitting should begin, from supine to 45º initially and if tolerated, the patient should be encouraged to progress to 60º and 90º if able. Pain levels and neurological signs / symptoms must be monitored during this process. If there is a significant worsening of any of these, patients should be returned to a position where these changes reverse and the stability of the spine reassessed.

(NICE, MSCC Guidelines, 2008)

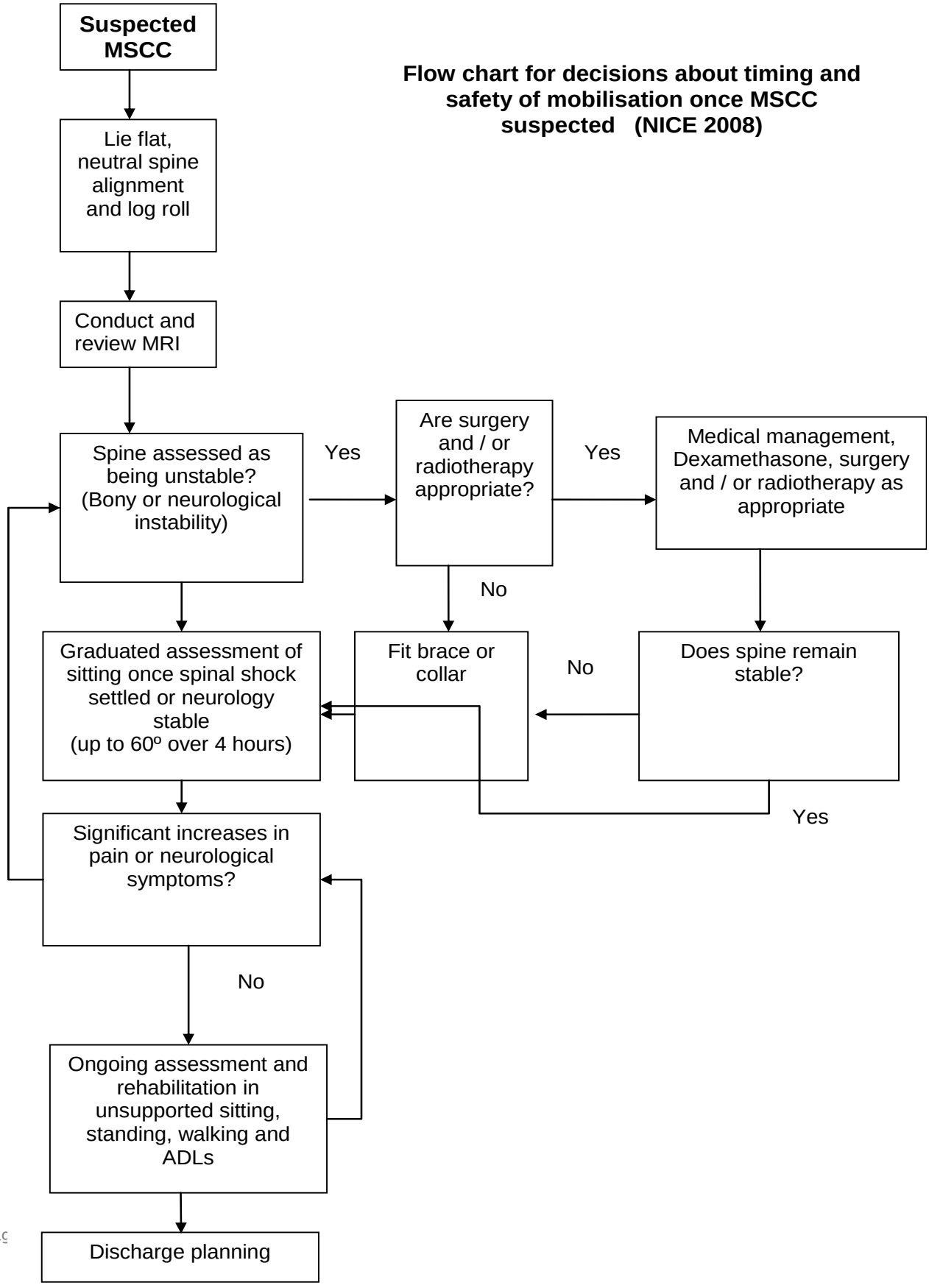
Discharge planning

Discharge planning should commence as soon as possible following admission and certainly as soon as the diagnosis has been confirmed. The patient and their carers should be involved in all discussions to ensure their wishes are respected and that the goals of discharge planning are realistic and achievable. Where community staff has already been

involved they should also be contacted for both a background report and to provide an update on the patient's status.

A patient with MSCC may be discharged / transferred between various healthcare settings during their episode of care and therefore effective communication strategies must be ensured to facilitate a seamless process.

Flow chart for decisions about timing and safety of mobilisation once MSCC suspected (NICE 2008)



Competence of MSCC coordinators

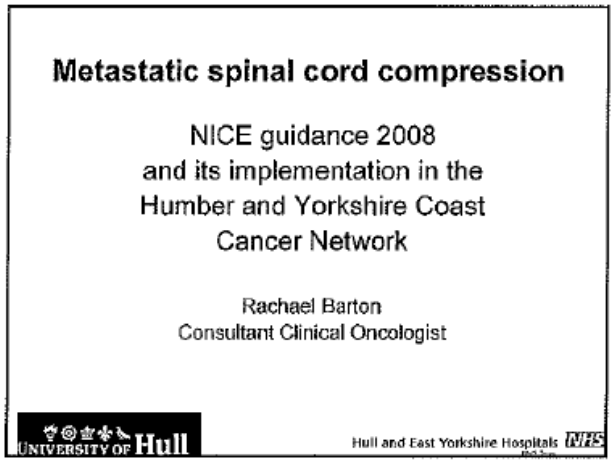
- A Registered nurse, at least band 6
- Have read the educational package and attended the training and assessment sessions.
- Have high level of communication skills.
- Good experience with cancer patients.
- Familiar to the MSCC referral pathway and referral form.
- Attend educational sessions on MSCC.
- Aware of the MSCC and acute oncology guidelines
- In good contact with the MSCC coordinators representative at meetings.
- Have an access to the two yearly MSCC group meeting minutes.
- Happy to participate in ongoing MSCC audit.

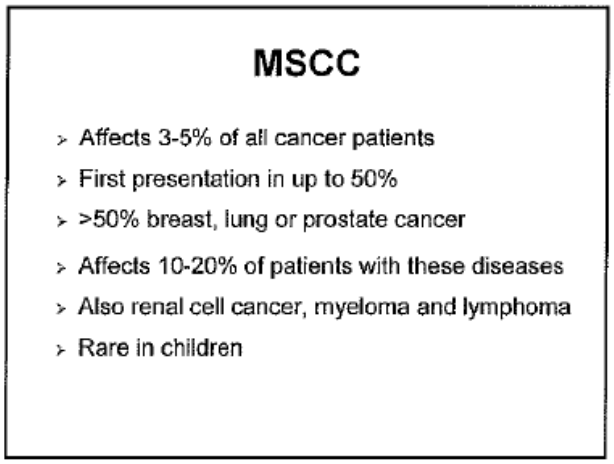
Presentations

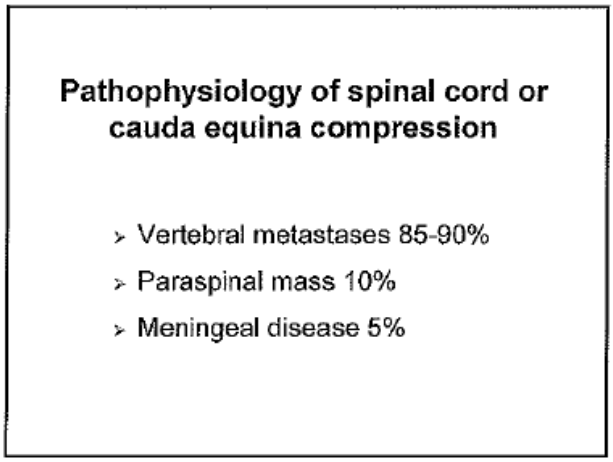
There is a presentation given with this training.

The slides for the presentation have been added here as **Appendix i**.

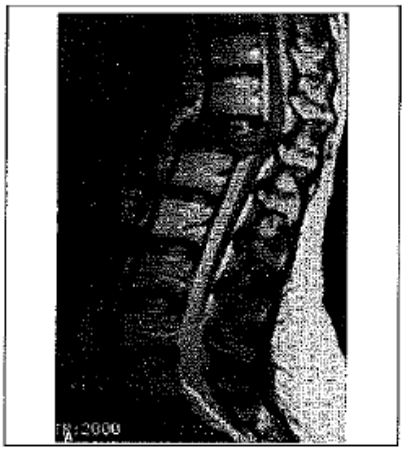
Appendix (i) MSCC Presentation Slides







- vertebral venous compression
- vasogenic oedema
- haemorrhage
- demyelination
- ischaemia
- white matter necrosis

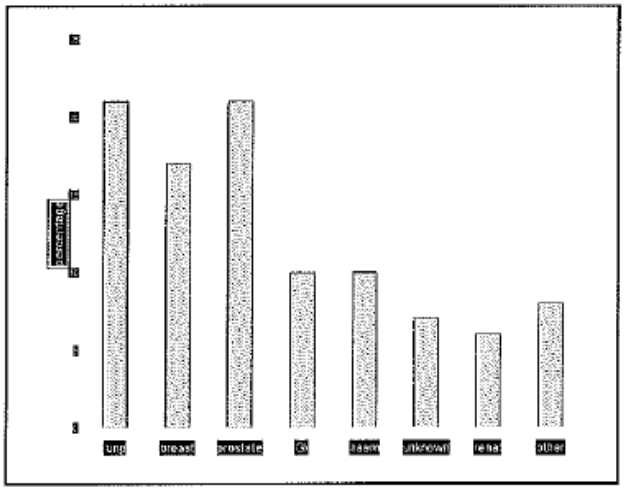


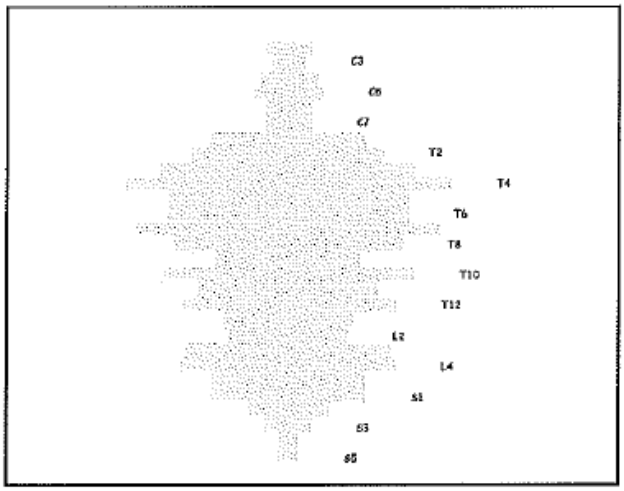
Natural history

3 centres in Scotland - Jan '98-April '99

- 319 patients with MSCC
- 203 male (64%); median age 65
- 59% lung/prostate/breast
- 248/319 (78%) gave account of symptoms

Levack et al Clin Onc 2002 14; 472-80





248 patients

Pain was band–like around thorax or abdomen or involving nerve roots in legs in 79%

Nerve root pain associated with localised back pain in 44%

Localised back pain alone less common (14%)

Correlation poor between:

1. Site of pain vs compression on MRI
2. Severity of pain and ability to walk
3. Clinical sensory level and MRI imaging (within 3 dermatomes in only 40%)
4. Abnormality on plain film / bone scan vs level on MRI

Delays in presentation & diagnosis

Median 66 days since reporting back pain before diagnosis of MSCC made (IQR 37-205 days)

Patients known to have cancer had shorter median time to diagnosis than those not known to have cancer (49 vs 90 days)

Diagnosis of MSCC made after a median of 15 days following referral to tertiary care (IQR 3-66 days)

At diagnosis only 18% could walk unaided

Multivariate analysis of prognostic factors in 2096 patients undergoing RT for MSCC

1. Motor function prior to RT
2. ECOG PS
3. Time from motor deficit to RT
4. Interval from initial cancer diagnosis
5. Primary tumour

Rades et al IJROBP 2008 **72(3)** 905-8

1. Motor function prior to RT
2. ECOG PS
3. Time from motor deficit to RT longer = better
4. Interval from initial cancer diagnosis
5. Primary tumour

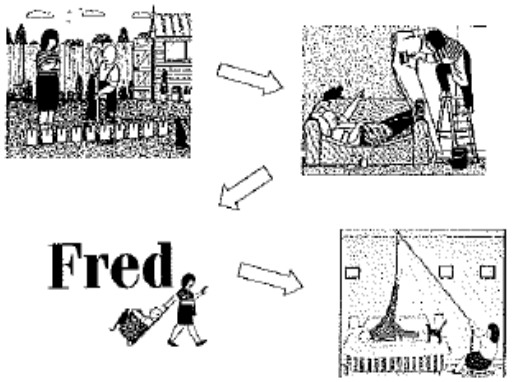
1. Motor function prior to RT
2. ECOG PS
3. Time from motor deficit to RT
4. Interval from initial cancer diagnosis longer = better
5. Primary tumour

1. Motor function prior to RT
2. ECOG PS
3. Time from motor deficit to RT
4. Interval from initial cancer diagnosis
5. Primary tumour

myeloma/lymphoma>breast>prostate>renal/colorectal>NSCLC

Paraplegia has a significant impact on the QoL of patient and carers

It is also a significant cost to the NHS



Inevitable?

With thanks to Rupert Fawcett cartoons

NICE Guidance 2008

Sets out a clear care pathway for the diagnosis, treatment, rehabilitation and ongoing care of patients with MSCC

Metastatic spinal cord compression:
Diagnosis and management of patients at risk of or with metastatic spinal cord compression

Full Guideline
November 2008
Developed for NICE by the National Collaborating Centre for Cancer

Published by the National Collaborating Centre for Cancer
2nd Floor, Front Suite, Park House,
Greyfriars Road, Cardiff, CF10 3AF

'NICE clinical guidelines are based on the best available evidence of clinical and cost effectiveness and are produced to help healthcare professionals and patients make informed choices about appropriate healthcare'

'While guidelines assist the practice of healthcare professionals, they do not replace their knowledge and skills'

Aims of management of patients with MSCC

- Identify early patients at risk of or with MSCC
- Institute appropriate diagnostic pathway
- Decide appropriate treatment if MSCC confirmed
- Begin treatment rapidly
- Begin rehabilitation early
- Support patient and family
- Set up ongoing care

Goals of treatment of MSCC

- Stabilisation of the spine
- Prevention of neurological deterioration
- Restoration of function and rehabilitation
- Pain relief
- Improvement in QoL

Early identification of patients at risk of or with MSCC

The symptoms and signs which are usually taught are those of established MSCC such as weakness of the limbs, bladder and bowel dysfunction and sensory loss.

Once paraplegia develops it is usually irreversible.

Early diagnosis, before signs develop, is paramount

NICE recommendations for early recognition of possible MSCC

Offer information (leaflet) to high risk patients and their carers which explains the symptoms of MSCC, and advises them (and their healthcare professionals) what to do if they develop these symptoms

Such information will be developed locally based on recommended format

Referral criteria

Patient with known cancer and symptoms of spinal mets:

- Contact coordinator within 24 hours
- MRI within 1 week

Patient with known cancer and symptoms of mets + symptoms/signs of MSCC:

- Contact coordinator immediately
- MRI within 24 hours

Patient without cancer diagnosis with suspicious spinal pain +/- mild, stable neurological symptoms/signs:

Standard care with careful observation.

Refer via coordinator if symptoms persist or progress

NICE recommendations for organisation of services

Patients may present to secondary care by a variety of routes

Local and network-wide protocols should be in place to ensure rapid access to a diagnostic and treatment service

NEYHCA (Cancer) level

CEG - primary, secondary and tertiary care representation

- links to site specific cancer CEGs

Executive lead

Meetings twice yearly

Executive lead and CEG will:

1. Ensure appropriate staff and services in place
2. Monitor regularly against national measures through audit
3. Advise on provision and organisation of services
4. Ensure consistency across NEYHCA (Cancer)

Local level

Each acute hospital will have a lead for MSCC who:

1. Represents their hospital at the CEG
2. Leads the development and implementation of local care pathways
3. Ensures effective communication between teams involved in the care of patients with MSCC
4. Contributes to audit

Hospitals without rapid access to MRI should have arrangements in place to transfer appropriate patients

Centres with capability to treat patients with MSCC must ensure:

1. 24 hour access to MSCC coordinator
2. Access to MRI within 24 hours of identification of likely MSCC
3. More rapid access to MRI if emergency surgery is planned
4. Access to radiotherapy within 24 hours of a diagnosis of MSCC, 7 days a week
5. Access to definitive surgery for patients deemed suitable
6. That surgery can be carried out before patients lose the ability to walk

MSCC coordinator

Each hospital treating patients with MSCC will identify individuals to fulfil the role of MSCC coordinator

The coordinator will be available 24 hours/day

The role may be incorporated into an existing on call service out of hours

MSCC coordinator

1. Provides the first point of contact for clinicians who suspect the development of spinal mets or MSCC
2. Assesses the requirement for and urgency of, investigation, transfer, and treatment
3. Advises on immediate care and seeks senior clinical advice as necessary
4. Gathers baseline information for audit purposes
5. Identifies an appropriate place for investigation and admission if required
6. Organises admission and transport

Senior clinical advisors

Every centre treating patients with MSCC should ensure 24-hour availability of senior clinical advisors to give advice and support to the MSCC coordinator and other clinicians, inform the decision-making process and undertake treatment where necessary

Planned organisation in NEYHCA (Cancer)

Treating centre is in Hull

- HRI for neurosurgery
- CHH for oncology

MSCC coordinator to be based in oncology centre

Role to be carried out by senior nurse practitioner on rota basis

Services already in place

24 hour on call service for neurosurgery, neuroradiology and oncology

Rapid MRI access within 24 hours

Rapid access to radiotherapy within 24 hours

Access to timely spinal surgery

Current requirements

1. Development and introduction of MSCC specific information leaflets
2. Development of coordinator role including education and supervision
3. Fax referral form – finalisation and distribution
4. Advertisement of role of MSCC service and contact details / criteria

5. Education of acute medical / A&E and surgical teams
6. Development of audit tools
7. Constitution of CEG and local teams
8. Assessment against national measures

Appendix (ii) Article from "Clinical Oncology" (2002)

Clinical Oncology (2002) **14**: 472–480
doi:10.1053/clon.2002.0098, available online at http://www.idealibrary.com on IDEAL®

Original Article

Don't Wait for a Sensory Level – Listen to the Symptoms: a Prospective Audit of the Delays in Diagnosis of Malignant Cord Compression

P. Levack*, J. Graham†, D. Collie†, R. Grant†, J. Kidd‡, I. Kunkler†, A. Gibson§, D. Hurman¶, N. McMillan||, R. Rampling||, L. Slider||, P. Statham†, D. Summers§, The Scottish Cord Compression Study Group

**Roxburghe House & Ninewells Hospital, Dundee; †Western General Hospital, Edinburgh; ‡Information & Statistics Division, NHS Scotland, Edinburgh; §Royal Infirmary of Edinburgh, Edinburgh; ¶Aberdeen Royal Infirmary, Aberdeen; ||Beatson Cancer Institute, Western Infirmary, Glasgow, U.K.*

ABSTRACT:
Aim: To report details concerning symptoms (especially pain) preceding the development of malignant cord compression (MCC); delays between onset/reporting of symptoms and confirmed diagnosis of MCC; accuracy of investigations carried out.
Methods: A prospective observational study examined the diagnosis, management and outcome of 319 patients diagnosed with MCC at three Scottish cancer centres between January 1998–April 1999. The process was considered from the perspectives of the patient, the GP and the hospital doctor.
Results: At diagnosis, most patients (82%) were either unable to walk or only able to do so with help. Pain was reported by nearly all patients interviewed (94%) and had been present for approximately 3 months (median=90 days). It was severe in 84% of cases, with the distribution and characteristics of nerve root pain in 79%. The site of pain did not correspond to the site of compression. Where reported, weakness and/or sensory problems had been noticed by the patient for some time before diagnosis (median intervals 20 and 12 days, respectively). Most patients reported early symptoms to their General Practitioner (GP) and diagnosis was established, following referral and investigation, approximately 2 months (median=66 days) later.
Conclusion: Patients who develop spinal metastases are at risk of irreversible spinal cord damage. Weakness and sensory abnormalities are reported late and identified even later, despite patients having reported pain for a considerable time. Patients with cancer who describe severe back or spinal nerve root pain need urgent assessment on the basis of their symptoms, as signs may occur too late. Plain films and bone scans requested for patients in this audit predicted accurately the level of compression in only 21% and 19% of cases, respectively. The only accurate investigation to establish the presence and site of a compressive lesion is magnetic resonance imaging (MRI). A referral guideline based on suspicious symptoms in addition to suspicious signs is suggested. Levack, P. *et al.* (2002). *Clinical Oncology* **14**, 472–480

Key words: Malignant cord compression, MRI, nerve root pain

Received: 29 October 2001 Final revised form: 27 March 2002 Accepted: 3 April 2002

Introduction

Metastatic bone disease is a common complication of cancer. When the vertebral body is involved, the resulting bone destruction may cause vertebral collapse, which in turn can cause compression of the spinal cord, cauda equina or individual nerve roots. Eventually irreversible neurological damage occurs, progressing to paraplegia. Compression may also result from a soft tissue tumour impinging directly on the spinal cord. The term malignant cord compression (MCC) applies to compression of both the spinal cord and the cauda equina.

Author for correspondence: Dr P. Levack, Roxburghe House, Royal Victoria Hospital, Dundee, DD2 1SP, U.K.

Studies have demonstrated consistently that MCC is diagnosed late in the evolution of a compressive lesion [1–7], and that ability to walk after treatment is directly associated with ability to walk at the time of diagnosis [2,8–10]. Once this ability is lost, recovery of mobility is unlikely, and many patients subsequently need 24 h nursing care.

If outcome is to be improved, the diagnosis of MCC must be made earlier, whilst the patient is still walking. Unfortunately the most widely recognized features of cord compression (weakness, sensory loss, bowel and bladder problems) occur late in the natural history of MCC. The clinical features of early compression, which occur before walking is affected, are less widely recognized. For most patients, symptoms begin when they are

0936–6555/02/060472+09 $35.00/0

Table 1 – Data collected from the patient, GP and hospital

Source	Data description
Patient	Date(s) of onset, site(s), severity and nature of pain
	Presence or absence of pain descriptors: deep, dull, burning, sharp, shooting, precipitation by coughing, sneezing, lying flat and bending
	Date(s) of onset, site and nature of sensory symptoms or weakness
	Date(s) of onset and nature of bowel and bladder problems
	Quality of life data (HAD, EUROQOL and SEIQoL). These data are reported separately
GP	The time of onset, site, nature, severity, and time reported to GP of back (or leg) pain, sensory symptoms, weakness, bladder or bowel problems
	The date and health professionals to whom the GP referred
Hospital (staff and/or records)	Demographic data including age, sex, residential postcode (using 1991 Carstairs deprivation categories which were matched on to records), primary tumour type, presence of other metastatic sites
	All relevant hospital admission and discharge dates before and after diagnosis
	All relevant imaging requested by GPs and clinicians
	Clinical examination findings (at the time of diagnosis) of weakness, mobility, sensory loss
	Timing and type of radiological investigation, and results of imaging from the onset of symptoms
	Date (and day of the week) of diagnosis

Treatment and follow-up (at 1, 4, 7 and 10 months) are reported separately.

in the community, and therefore they tend to present initially to their General Practitioner (GP). They may, or may not, be known to have cancer at presentation, and may be admitted under various hospital specialists.

The aim of this study was to assess the natural history of MCC from the onset of patient symptoms to the time of diagnosis. Specifically the study aimed to document delays in the diagnosis of MCC, to analyse their duration and where they occurred. In addition, the process of diagnosis was examined from the GP, hospital doctor and patients' perspectives.

Methods

From 1 January 1998 to 14 April 1999, sequential patients diagnosed with MCC at any of three oncology centres in Scotland (The Department of Oncology, Western General Hospital, Edinburgh; The Beatson Oncology Centre, Western Infirmary, Glasgow; and Aberdeen Royal Infirmary) were recruited to the study.

The criterion for entry to the study was a definitive diagnosis of malignant cord or cauda equina compression – most often by magnetic resonance imaging (MRI) of the spine. This study did not include any patients who might have been suspected to have MCC, but were not referred for any imaging. However, in the two larger centres, we were confident that all cases of MCC diagnosed were included in the study. MCC was defined as compression, flattening or distortion of the spinal cord or cauda equina by extradural (bony or epidural) tumour, or by intradural (leptomeningeal or intraparenchymal) tumour. Patients were identified from daily review of emergency spine MRI scans, radiotherapy referral lists and referrals from clinicians involved in the management of MCC.

Approval for data collection was obtained from all relevant Primary Care and Acute Hospital NHS Trusts' ethics committees. Individual consultants were also asked in advance for permission to interview their patients with MCC. Patients were asked whether they would be willing to participate in the interview component of the study, and written consent obtained.

Table 1 provides a general description of the data items collected. When recording pain suffered by patients, localized back pain was defined as pain in and around the vertebral column. Nerve root pain was defined as pain in a dermatomal distribution, affecting one or both sides of the body, such as bilateral thoracic root pain, unilateral anterior thigh (L2/3) pain or bilateral sciatic (L5/S1) pain, and often characterized by qualities such as burning, shooting or tingling. The severity of pain was graded using a visual analogue score (VAS) in which 0 represented "no pain" and 10 the "worst pain imaginable".

Data Entry and Analysis

A research assistant in each centre collected and recorded all data. Data cleaning and statistical analysis were performed by the study statistician (J.K.; Information and Statistics Division, NHS, Scotland). Non-parametric data were compared using the Mann–Whitney U-test when comparing two groups and the Kruskal–Wallis test when there were three or more groups.

Results

Patient Population

Three hundred and twenty-four clinical episodes of compression were recorded in relation to 319 patients (203 male, 116 female). Eighty-nine per cent of patients were over 50 years of age at diagnosis; the median age

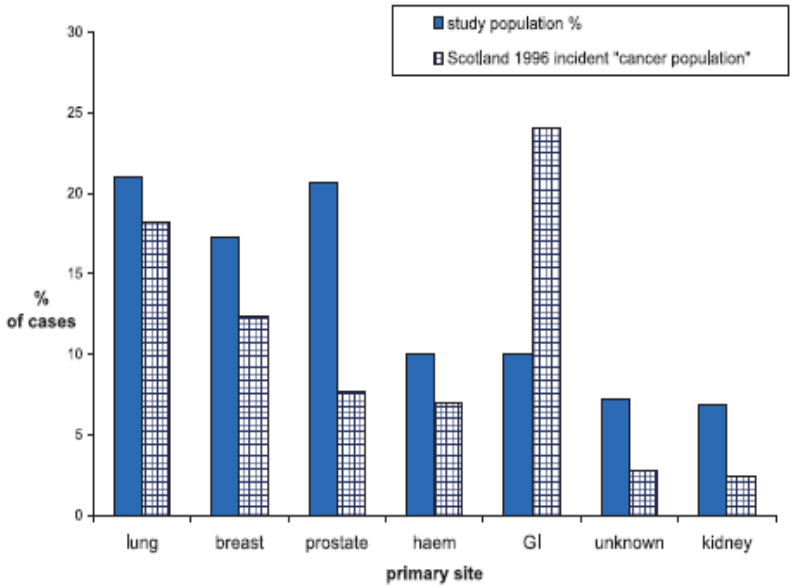


Fig. 1 – Primary tumour type of patients with MCC compared with incidence of primary tumours in Scotland 1996.

was 65. The commonest primary tumours were lung, prostate and breast, which together accounted for 59% of all cases. Ten per cent (32) of tumours were from the gastrointestinal tract and a further 10% were of haematological origin (myeloma, lymphoma, chronic lymphatic leukaemia). With the exception of gastrointestinal (GI) cancer, the percentage of patients seen with MCC (Fig. 1) was greater than predicted from the national cancer incidence [11], and this was most evident in prostate cancer. Although the incidence of metastatic bone disease secondary to GI cancer may be increasing, the metastatic potential for bone remains lower than the other common cancers, namely lung, prostate and breast. However with improvements in survival, morbidity related to metastatic disease from GI cancer may become more evident. In 23 cases (7%) the site of primary tumour was never identified.

Sites of Cord Compression

The level of compression was defined in terms of the vertebral body at which the uppermost part of neural compression occurred. The thoracic spine was the commonest site of MCC accounting for over two thirds of episodes in which a clear level was identified – similar to previous reports [2,7,12,13]. Thirty-five per cent occurred in the upper thoracic (T1–T6) region and 33% in the lower (T7–T12) region. Twenty-one per cent of cases occurred in the lumbar region, 7% in the cervical region, and 4% in the sacral region. Two or more concurrent compressive levels were identified in 55 out of 324 patients at imaging (17%).

Cord Compression as the First Presentation of Malignancy

Two hundred and forty-seven patients (77%) were known to have cancer before the imaging diagnosis of MCC was made. In the remaining 72 patients (23%), a diagnosis of MCC was the presenting symptom of malignancy.

Clinical Symptoms Described by Patients

Two hundred and sixty-one of 319 patients (82%) consented to be interviewed and/or for their GP to provide further information. Those patients who agreed, were interviewed a median of 3 days after they were told of their diagnosis of MCC, thus allowing the patient 48 h to consider whether or not to take part. Two hundred and forty-eight of the 261 patients who agreed to be interviewed, were able to provide a detailed personal history of their symptoms. The pattern and sequence of symptoms described by patients were very similar. Two hundred and thirty-three of 248 patients (94%) reported pain, either spinal nerve root and/or localized back pain. Seventy-nine per cent (196/248) of patients who provided a detailed history, had nerve root pain (Fig. 2), either alone in 35% (86 cases) or in association with localized back pain in 44% (110 cases). Nerve root pain was most commonly thoracic (band-like around chest or abdomen) or involving upper lumbar roots (anterior thigh pain), and was most often bilateral (66%). Fourteen per cent (35 cases) had localized back pain alone and in 1% (two cases) the nature of the pain was unclear.

Most patients (197/234; 84%) reported their pain to have been progressive, and latterly severe. The median intensity on the visual analogue pain scale was 8/10. Nearly one-third (29%) of patients assessed the severity of their pain as "the worst imagined" i.e.10/10 or even "11/10".

Patients generally selected several words (median=3) from the list of nine characteristics, to describe their pain (Fig. 3). The most common descriptors were sharp

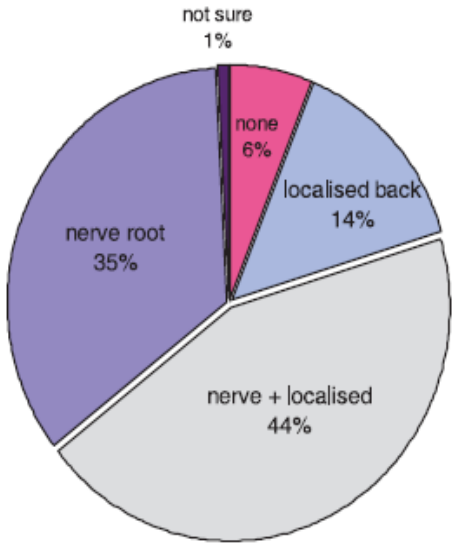


Fig. 2 – The presence and nature of pain reported by interviewed patients.

(59%), shooting (41%) and/or deep (36%) and the most common precipitating factors were coughing (42%), bending (40%) and/or sneezing (35%). Other qualities namely burning (30%), dull (28%) and precipitated by lying flat (19%) were less frequent. Patients often added their own adjectives, the commonest being "like toothache" (10%) and made worse by moving (14%). Pain characteristics described were similar for both lumbosacral and thoracic pain.

There was considerable discordance between the level of pain and the structural level of compression (Fig. 4). For example, more than half of patients (54%) with upper thoracic compression (T1–T6) had lumbosacral pain and conversely a similar proportion (54%) with proven lumbosacral compression had thoracic pain.

Less than one in five patients (18%) were able to walk by the time a diagnosis was made. Patients commonly reported falls, and most patients (210/248; 85%) had noticed weakness or difficulty walking beforehand. The median duration of weakness was 20 days [interquartile (IQ) range 7–132 days].

There was no association between ability to walk and the patient's self-reported pain level as originally given on the audit form ($P=0.99$; Kruskal–Wallis test). In particular, patients who reported a pain score of 10/10 were just as likely to walk without help as those with much lower pain scores. This is illustrated (with pain scores grouped) in Fig. 5.

The majority of patients (168/248; 68%) had noticed altered sensation before the diagnosis of MCC, for a median of 12 days (IQ range 4–41 days). One hundred and thirty-nine patients (56%) reported at least one problem with passing urine, one quarter having urinary retention. Other symptoms include urinary incontinence (15%), frequency (6%), urgency (3%) and hesitancy (14%). One hundred and eighty-three (74%) of patients reported bowel problems of which by far the commonest was constipation, in 164 patients (66%). Many of these patients were on moderate or strong opioids and the constipation was commonly attributed to medication. Five per cent reported faecal incontinence.

Clinical Assessment in Hospital

In 84% of all episodes (272/324), weakness was detected on clinical examination. In 58% (87/324), sensory abnormalities were found on examination, and in 169 of these (52% of all patients), a sensory level was noted. The clinical level of sensory abnormality corresponded poorly with the level of cord compression identified on MRI imaging, varying by up to 10 dermatomes below or above the compressive lesion. In those in which a

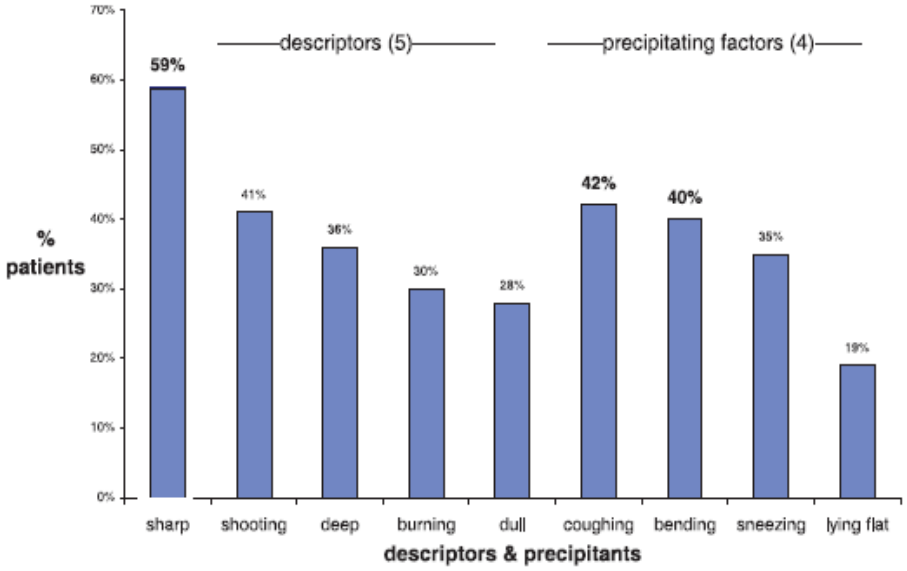


Fig. 3 – Pain characteristics and precipitating factors.

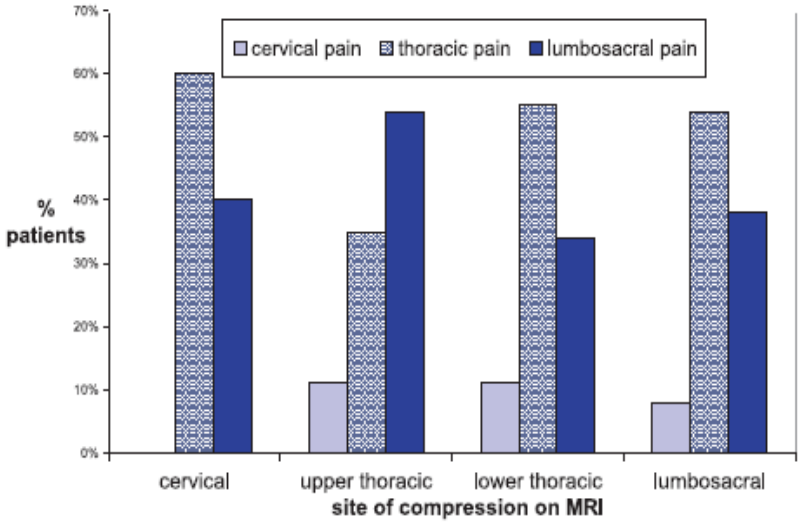


Fig. 4 – Comparison of level of pain and MRI level of compression.

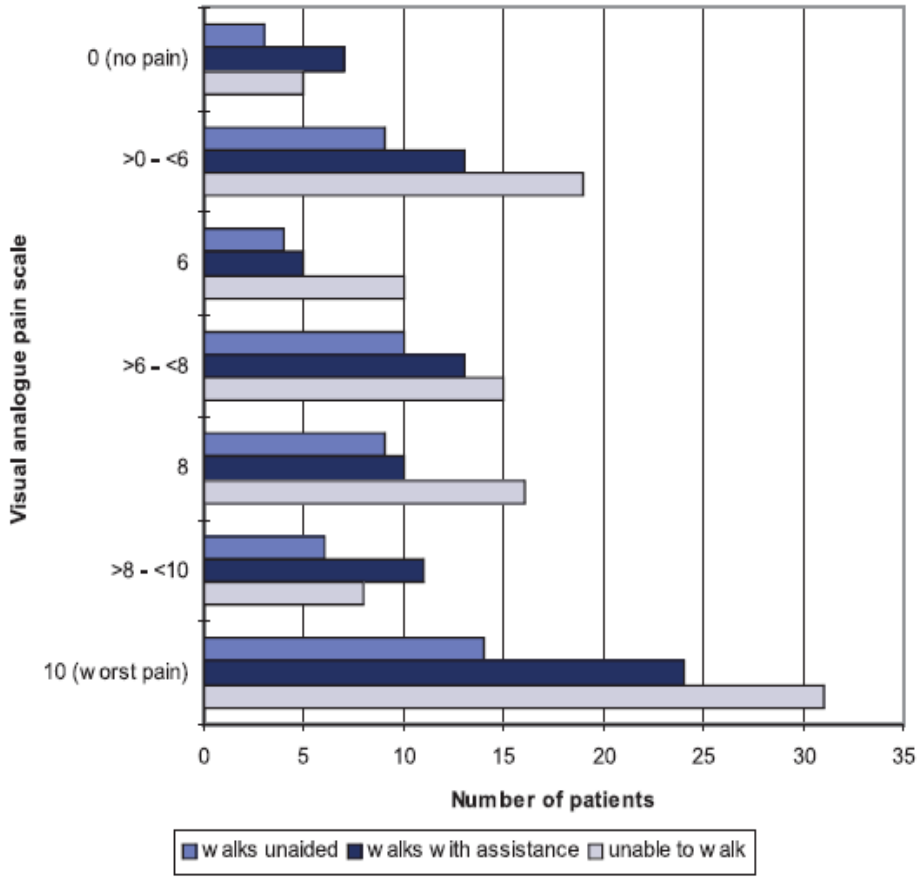


Fig. 5 – Ability to walk at diagnosis versus self-assessed pain level in consenting patients (n=242).

sensory level and MRI level of compression could be compared (127 patients), the level was within three dermatomes (either above or below) in only 40% of cases. Therefore, considering the whole study population of 324 patients with MCC, a sensory level was of value in identifying the level of compression in only 16% of the MCC study group.

Delays in Diagnosis

We audited the chain of events and timing of them during the period from symptom onset to diagnosis. The nature of the study created some difficulties with 'time-line' analysis. Eighty per cent of patients in the study consented to give a detailed history, and account has to

be taken of how representative this subset was of the overall study population. Some date comparisons, for example the duration of back pain, were only relevant to those patients who had back pain. Hence the denominators changed depending on the patient subgroup being analysed, for any particular comparison between one date and another. Furthermore some dates were approximate – even though they were as accurate as the patient could remember.

The patient

Patients experienced pain (localized back and/or nerve root pain) for approximately 3 months (median=90 days; IQ range 37–205 days) before a definitive diagnosis was established and treatment given. From the point at which the patient reported their first relevant symptom to a health professional, it was approximately 2 months (median 66 days, IQ range 37–205 days; $n=152$;) until a compressive syndrome developed which was recognized, definitively diagnosed and documented.

Most patients interviewed (83%; 206/248), told their GP about the pain within 3 weeks (median=18 days), and at this stage 60% were already known to have a history of cancer. Patients who were already known to have cancer at the time they first developed nerve root pain ($n=119$), were diagnosed significantly more quickly (median 49 days) than those who were not known to have cancer (median 90 days; n=75; $P<0.001$, Mann–Whitney test).

Primary care

"GP referral" was defined as referral for a professional opinion to either a hospital doctor (within one of a range of specialties), a physiotherapist or other health professional. The GP referred approximately 3 weeks after the patient had first told them of their symptoms (median=18 days; IQ range 2–66 days). It was no faster for those patients known to have cancer at the time of telling their GP ($P=0.32$).

After referral

A diagnosis of MCC was made a median time of 15 days after referral (IQ range 3–66 days); thus in a quarter of patients for whom this time interval was calculable, the diagnosis was made 2 months or more after referral. The rate of diagnosis of MCC increased through the week and was maximal on a Friday. Few patients were diagnosed and treated at the weekends (Fig. 6), presumably reflecting the lack of access to MRI outside the working week.

Radiological Investigations

A wide range of investigations, including plain films, scintigraphy, computed tomography (CT) and MRI, were undertaken in the period from symptom onset to the time of diagnosis of MCC. Most were performed as part of the investigation of unexplained back pain, although a few were performed as part of the staging of primary malignant disease (e.g. locally advanced breast cancer), hence the inaccuracy of plain films and scintigraphy may be a slight overestimate.

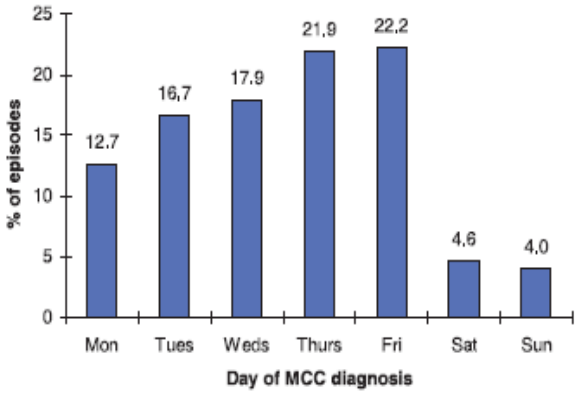


Fig. 6 – Day of the week on which MCC was diagnosed.

Accuracy of plain films

Plain films were obtained in over half (57%) of patients before a definitive diagnosis of MCC was established; they were often arranged by the GP during the period before referral. X-rays were often of an area, which subsequently proved not to be the site of compression, but this was understandable considering that the site of pain and of compression did not correspond. The most common request was for a lumbar spine x-ray, whilst the commonest site of compression was the thoracic spine. Using the plain film sign of significant vertebral collapse (50% or more loss of vertebral height), as an indicator of MCC, plain films were highly inaccurate in predicting the level of compression. Vertebral collapse was seen in 60/187 (32%) of plain films, and in 39 of these the level of compression was confirmed on MRI. Thus in those patients who had plain films, the films obtained correctly predicted the subsequent level of compression in 21%.

Accuracy of isotope bone scintigraphy

One hundred and thirty-nine patients underwent bone scintigraphy for symptomatic back pain. Using the site of greatest activity as the most likely level of compression, bone scintigraphy was also a poor predictor of the level of compression. Forty-nine examinations had spinal hot spots suggestive of extensive bone destruction and in 26 of these, the site of greatest activity correctly predicted the level of compression, as identified on MRI. Twenty suggested an incorrect level, and three had no confirmation. Overall scintigraphy correctly predicted the level of cord compression in 26/139 (19%) examinations.

MRI

MRI was equal to or superior to all other imaging modalities at detecting cord compression. MRI detected more collapsed vertebrae than plain films, and was equivalent to bone scintigraphy in the detection of metastatic disease in adjacent and non-adjacent vertebrae.

Discussion

It is clear from our study, that at present, the majority of patients are diagnosed far too late for treatment to be of any value. Only one patient in five (18%) was able to walk without any form of help at diagnosis, and this finding was not influenced by patient age ($P=0.33$) or deprivation category ($P=0.45$). There are long delays between the onset of symptoms and diagnosis of MCC, in patients with and without a known diagnosis of malignancy.

Hence it is apparent that the current process of diagnosis is failing many patients, despite the existence of a non-invasive highly effective method of imaging (MRI). The objective should be, to alter current practice to diagnose MCC while patients are still walking. Instead of making a diagnosis of MCC, which is beyond all suspicion, i.e. based on "hard" clinical signs, the patient who has malignant epidural disease, and other patients at high risk of developing MCC, need to be identified earlier.

Although a lot of emphasis is put on clinical signs of MCC, in practice they are often identified late, if at all. Problems with walking are often attributed to pain, but as can be seen from the data presented here, patients reporting their pain to be 10/10 were just as likely to be able to walk as those whose pain was much less. A sensory level was noted in half the patients (52%) but by the time it was noted, the majority of these patients were unable to walk and therefore the presence of a sensory level does not help in detecting MCC before motor loss.

There is a lack of awareness in both primary and secondary care of the early symptoms of MCC. Symptoms in the cancer population have a different significance to symptoms in the general, non-cancer population. Progressive and severe pain in cancer patients is usually related to cancer progression or recurrence, and a recent study indicated that 92% of severe pain in cancer patients was due to tumour involvement [14]. In our study, severe nerve root pain was strongly associated with epidural disease and was reported by patients long before weakness.

Furthermore in this study, patients' descriptions of pain – its severity and its characteristics – were remarkably consistent. Using a checklist of cancer pain syndromes previously described [15], the Task Force on Cancer Pain of the International Association for the Study of Pain [14] identified 22 cancer pain syndromes and the pain attributed to neural involvement was often described as amongst the most intense. Although Bayley *et al.* in a recent publication [16] did not find the presence or absence of pain, or the use of opioid analgesia to be an independent prognostic factor for occult MCC, in patients with known metastatic bone disease they did not define the nature of pain, the presence or absence of nerve root pain or the means by which a pain history was taken.

The diagnostic value of the words patients use to describe their pain has been examined by several authors [12,17,18], mainly to differentiate nerve root pain from non-nerve root pain. Such studies usually included patients with a mixture of malignant and non-malignant conditions. In our study, in which most patients had MRI-proven confirmation of malignant compression of the spinal cord, pain was most commonly described as sharp and precipitated by coughing or bending, irrespective of whether the pain was thoracic or lumbosacral. Lying flat was the least frequently reported quality. Our study found that severe nerve root pain was strongly associated with root and cord compression, and this pain syndrome can be recognized by making a careful pain assessment including its distribution, severity, the words used to describe it and the factors that provoke it.

With regard to investigations, this study has shown that there is a lack of awareness and/or access, to the most useful investigation of back pain in malignancy. We have shown that plain films are an insensitive method of detecting bone metastases compared to MRI, particularly in tumours not causing cortical bone destruction, and bone scintigraphy is insensitive to the presence of neural compression. Yet much time was spent by hospital doctors and GPs, arranging plain films and bone scintigraphy, which, in many cases added little to establishing a diagnosis of root or cord compression. Indeed it is highly likely that initial investigation with plain films and/or bone scintigraphy contributed to delays in diagnosis in some cases.

The specific issues the clinician wishes to answer by radiological investigation, are (1) whether there is tumour compressing the cord or a nerve; (2) whether the spine is stable and (3) what treatment should be used and on what site. These questions can only be answered satisfactorily with MRI. The existence and the quality of the pain appear more important than the site of pain, as the latter correlated poorly with site of compression. Neither the site of pain, nor the location of a sensory level, (if any) is reliable enough to establish the diagnosis of MCC or select the level of radiological assessment. Therefore MRI of the whole spine is the only suitable investigation, in patients with severe back or nerve root pain and known malignancy. Other investigations probably delay diagnosis because of waiting times and the false reassurance they can give to the patient's clinician.

Unfortunately MRI is not available in many hospitals out of hours, and the low percentage of patients in whom MCC was confirmed by MRI at the weekends, contributes to the delay in diagnosis and management. MRI is often difficult even to arrange during normal

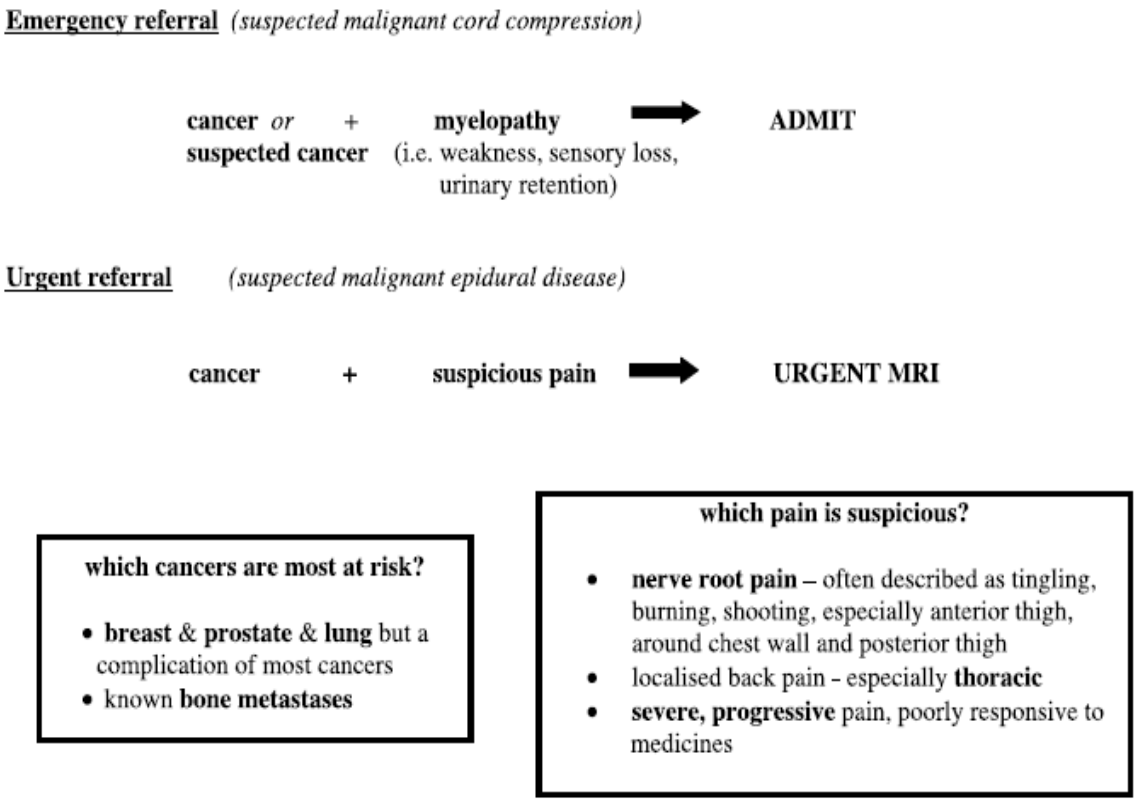


Fig. 7 – Proposed referral guideline.

working hours, as patients are selected on the basis of having "clear evidence of compression". Those patients without significant weakness, and often those without a sensory level, may fail to qualify. Despite widespread awareness of the need to diagnose MCC early, the very justification for MRI often depends on clinical findings, which occur late.

This study also highlights the problem of "parallel care" of patients who, following referral, remain in the primary care environment but are also in the hospital out-patient system. It was clear from listening to patients, that whilst investigations were pending, symptoms often deteriorated. After making the referral, the GP was not always able to influence arrangements and timing of planned investigations. Despite the recognized importance of early diagnosis, there frequently appeared to be little sense of urgency.

Certain categories of patients are at risk of MCC, specifically patients who are already known to have cancer when they first develop pain, who are over the age of 50, and those with breast or prostate cancer with known bone metastases. Prostate and breast cancer is widely recognized to metastasise readily to bone and a recent study has demonstrated the high incidence of occult epidural disease and MCC, in patients with prostate cancer, in whom neurological examination was normal. [16]. The likelihood of occult epidural disease was highest in those patients with hormone refractory disease, and extensive (>20) bone metastases detected on bone scan.

MCC is a clinical emergency and delays in diagnosis and treatment have devastating consequences for patients and their families. Consequently GPs are frequently exhorted to refer patients with cord compression early, whilst at the same time being discouraged from over-referring patients who have "uncomplicated" back pain. The Royal College of General Practitioners "Guidelines for the management of acute low back pain" [19] alert the practitioner to specific symptoms and signs, which may indicate serious disorders. However the guideline is intended for the general population, in which acute low back pain due to degenerative disease is common. It differentiates back pain into three separate categories: simple mechanical backache, nerve root (leg) pain and possible serious spinal problem. There are no guidelines specifically for patients already known to have cancer and who develop back pain, and it is clear from our findings that nerve root (leg) pain and a serious spinal problem (MCC) frequently co-exist.

This study confirms that despite a long history of painful symptoms and a past diagnosis of cancer, the diagnosis of MCC is still being made late. Therefore, in order to:

(1) Reduce delays in diagnosis and referral, the authors propose a national programme of awareness of MCC, in order to highlight in particular the association of severe nerve root pain with epidural disease, in patients with cancer. The ability to distinguish nerve root pain from non-nerve root

pain needs to be considerably improved. Patients is our study did not delay long before seeking help, but it may be appropriate for patients to be educated as above.

(2) Ensure an efficient and accessible referral process is in place, referral guidelines are currently being developed to urgently image with MRI patients who are "at risk of having epidural disease or evolving compression" as shown in Fig. 7. This process however, will almost certainly depend on increased MRI availability.

Acknowledgements. This study was funded by a grant from CRAG Clinical Research and Audit group of the Scottish Office, and the report was submitted in July 2001. The Scottish Health Executive has subsequently agreed to implement the report's findings.

References

1 Bach F, Larsen BH, Rohde K, *et al*. Metastatic spinal cord compression. Occurrence, symptoms, clinical presentation and prognosis in 398 patients with spinal cord compression. *Acta Neurochir* 1990;107:37–43.
2 Brown P, Stafford S, Schild S, Martenson J, Schiff D. Metastatic spinal cord compression in patients with colorectal cancer. *J Neurooncol* 1999;44:175–180.
3 Gilbert R, Kim J, Posner J. epidural spinal cord compression from metastatic tumour: diagnosis and treatment. *Ann Neurol* 1978;3(1):40–51.
4 Grant R, Papadopoulos S, Greenberg H. Metastatic epidural spinal cord compression. *Neurol Clinics* 1991;9:825–841.
5 Husband DJ. Malignant spinal cord compression: prospective study of delays in referral and treatment. *BMJ* 1998;317:18–21.
6 Husband DJ, Grant KA, Romaniuk CS. MRI in the diagnosis and treatment of suspected malignant spinal cord compression. *Br J Radiol* 2001;74:15–23.
7 Rodichok LD, Harper GR, Ruckdeschai JC. Early diagnosis of spinal epidural metastases. *Am J Med* 1981;70:1181–1188.
8 Hacking H, Van As H, Lankhorst G. Factors related to the outcome of inpatient rehabilitation in patients with neoplastic epidural spinal cord compression. *Paraplegia* 1993;31:367–374.
9 Huddart R, Rajan B, Law M, Meyer L, Dearnaley D. Spinal cord compression in prostate cancer: treatment outcome and prognostic factors. *Radiother Oncol* 1997;44:229–236.
10 Kim R, Spencer S, Meredith R. Extradural spinal cord compression: analysis of factors determining functional prognosis – prospective study. *Radiology* 1990;176:279–282.
11 Scottish Cancer intelligence Unit. *Trends in cancer survival in Scotland* 1971–1995. Edinburgh: ISD, 2000.
12 Cook A, Lau T, Tomlinson M, Vaidya M, Wakely C, Goddard P. Magnetic resonance imaging of the whole spine in suspected malignant cord compression: impact on management. *Clin Oncol* 1998;10:39–43.
13 Pigott K, Baddeley H, Maher E. Pattern of disease in spinal cord compression on MRI scan and implications for treatment. *Clin Oncol* 1994;6:7–10.
14 Caraceni A, Portenoy RK. An international survey of cancer pain characteristics and syndromes. IASP Task Force on Cancer Pain. International Association for the Study of Pain. *Pain* 1999;82:263–274.
15 Cherny NI, Portenoy RK. Cancer pain: principles of assessment and syndromes. In: Wall PD, Melzack R, eds. *Textbook of pain*, 3rd edn. 1994;787.
16 Bayley A, Milosevic M, Blend R, *et al*. A prospective study of factors predicting clinically occult spinal cord compression in patients with metastatic cord compression. *Cancer* 2001;92:303–310.
17 Bennett M. The LANSS pain scale: The Leeds assessment of neuropathic symptoms and signs. *Pain* 2001;92:147–157.
18 Boureau F, Doubrere JF, Luu M. Study of verbal descriptors in neuropathic pain. *Pain* 1990;42:145–152.
19 Royal College of General Practitioners. *Clinical Guidelines for the management of acute low back pain*. London: RCGP, 1999.

Appendix (iii) MSCC Service Poster


NHS
Hull and East Yorkshire Hospitals NHS trust
Malignant/Metastatic Spinal Cord Compression (MSCC)
If you suspect (or have confirmed by MRI) Malignant/Metastatic Spinal Cord Compression please contact the MSCC Coordinator immediately on:
Tel No. 07498782361
Or CHH 01482 875875 Bleep 500
For more information including the MSCC Pathway, Guidelines and MSCC Referral form visit:
http://intranet.hey.nhs.uk/mscc
MSCC Referral Fax No. 01482 461474

Appendix (iv) Pathway for Malignant / Metastatic Spinal Cord Compression (MSCC)

Hull and East Yorkshire Hospitals NHS Trust

PATHWAY FOR MALIGNANT SPINAL CORD COMPRESSION (MSCC)
(Adapted from NICE guidelines available at http://guidance.nice.org.uk/CG75)

Patients with a known diagnosis of cancer	**Patients without a known diagnosis of cancer**
The local MSCC coordinator should be contacted **urgently** (within 24 hours) to discuss the care of patients with known cancer and any **symptoms suggestive of spinal metastases** (see below)	Patients developing suspicious pain should be reviewed frequently and referred **within 24 hours** if they develop progressive pain or other **symptoms suggestive of spinal metastases** (see below)

SYMPTOMS SUGGESTIVE OF SPINAL METASTASES

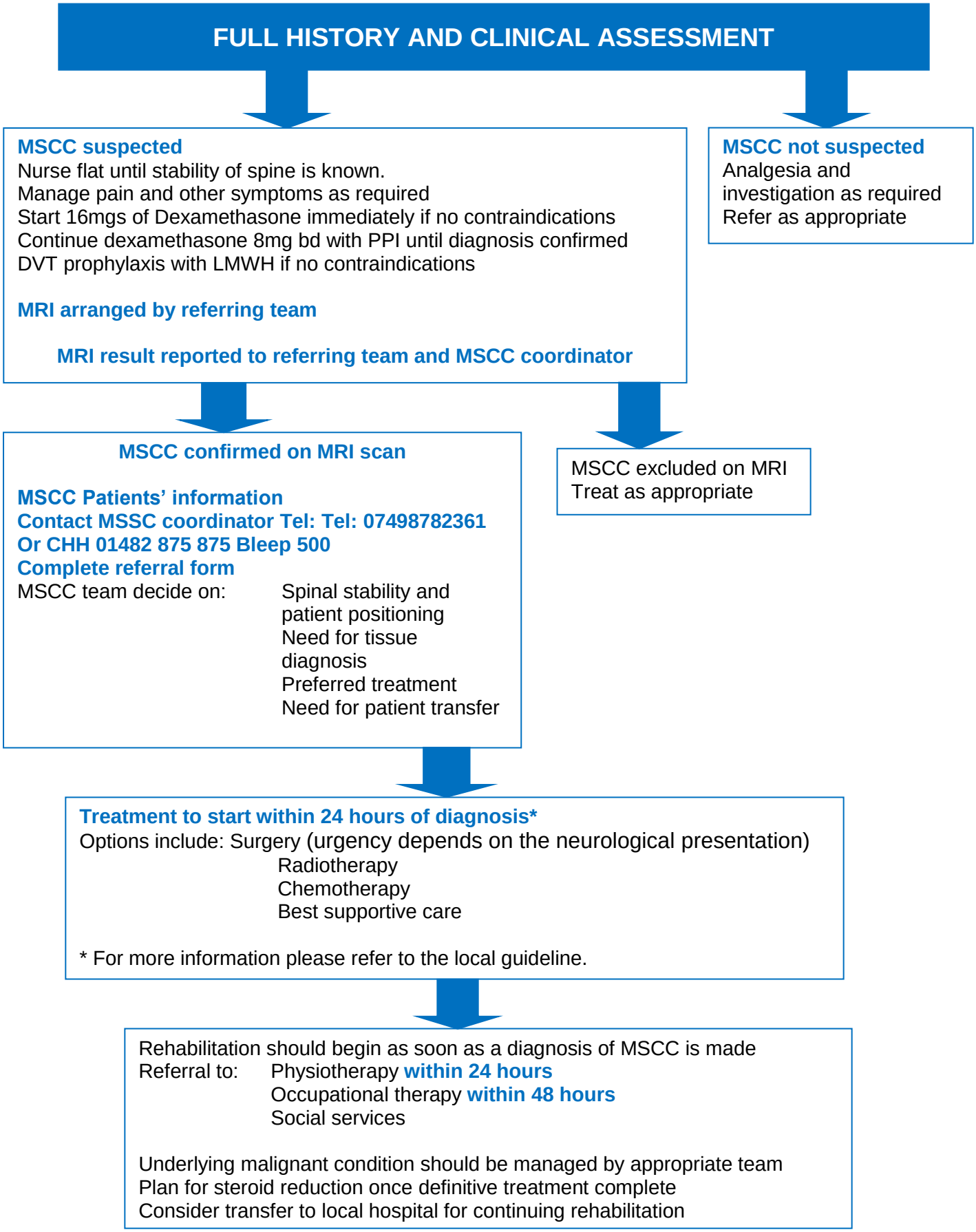
- Pain in the thoracic or cervical spine
- Progressive lumbar spinal pain
- Severe unremitting spinal pain
- Spinal pain aggravated by straining (for example, opening bowels, coughing or sneezing)
- Localised spinal tenderness
- Nocturnal spinal pain preventing sleep

SYMPTOMS OR SIGNS SUGGESTIVE OF MSCC SHOULD BE VIEWED AS AN ONCOLOGICAL EMERGENCY

The local MSCC coordinator should be contacted **immediately** to discuss the care of patients with or without known cancer with symptoms suggestive of spinal metastases who have **any** of the following **neurological symptoms or who have neurological signs suggestive of MSCC or cauda equina compression**

Neurological symptoms include radicular pain, any limb weakness, difficulty in walking, sensory loss or bladder / bowel dysfunction

Hull and East Yorkshire Hospitals NHS Trust



Appendix (v) NEYHCA (Cancer) Metastatic / Malignant Spinal Cord Compression Referral Form

Metastatic / Malignant Spinal Cord Compression (MSCC) Referral Form

*Please fill all fields and **do not** use the return key during typing

Please contact MSCC coordinator before sending on 07498782361

**(Failure to reach the MSCC coordinator please contact CHH 01482 875 875 bleep 500 or Registrar oncall)*

MSCC treatment referral: Date of referral : Time of referral: Date of admission:	Referred by : Contact number: Extension: Bleep/Pager:

Patient Details and relevant information	
Surname: Forename: DOB: Address: Telephone No.	Previously known to Oncologist: Y ☐ / N ☐ Name: Oncologist aware of Referral: Y ☐ / N ☐ **Prior MDT Discussion Y ☐/ N ☐** Hospital Date Outcome •

Background Tumour information	**MSCC clinical information**
Primary: **Current Management:** Chemo ☐ Radiotherapy ☐ Hormone ☐Biological ☐ Best supportive care ☐ **Previous MSCC: Y ☐ / N ☐** Date: Area affected: Treatment received: Radiotherapy ☐ Surgery ☐ Both ☐ Other:	**Time and Date of MSCC was first suspected:** - **Walking Status:** Normal ☐ Unsteady: Y ☐/ N ☐ Since(date): Not Ambulant: Y ☐ / N ☐ Since (date): **Spinal stable: Y ☐ / N ☐ / Not Known ☐** Recommandation: •
MRI Whole spine: Not Done ☐ (Reason:) Done ☐ Location: Time - Date requested: - Time - Date done: - Outcome:	**Other relevant Information:** • • • • • • •

Please complete this form as fully as possible