Sharing good practice

**METASTATIC SPINAL CORD COMPRESSION**

**Helen Tyler**
Macmillan Therapies Service Manager and
Lead AHP, South Wales Cancer Network

**Lena Richards**
Lead Network MSCC Coordinator,
The Christie NHS Foundation Trust

**Andrea Chatterley**
Macmillan Nurse Specialist
Malignant Bone Disease,
University Hospitals of North Midlands NHS Trust

**Sandra Curtis**
MSCC Coordinator,
Lancashire Teaching Hospital
NHS Foundation Trust

**Kate Baker and Kathryn Elias**
Macmillan MSCC Service Improvement Leads,
South Wales Cancer Network

**Dr Cathy Hutchison**
Cancer Consultant Nurse,
Beatson West of Scotland Cancer Centre

**Anita Killingworth**
Macmillan Advanced Nurse Practitioner Orthopaedic Oncology,
The Royal Orthopaedic Hospital NHS Trust

**Jackie Whigham**
Acute Oncology Project Manager,
Edinburgh Cancer Centre,
Western General Hospital

**Deborah Kerr**
Macmillan Service Improvement Lead for Oncology, Northern Ireland Cancer Network

**Clodagh O’Brien**
Former Macmillan MSCC Project,
Northern Ireland Cancer Network

Summer 2015
Metastatic spinal cord compression

Metastatic spinal cord compression (MSCC) is a highly complex and debilitating complication of cancer. It affects 5–14% of people with cancer.1

People who have cancer – whether they have a known primary diagnosis or not – are at risk of the cancer spreading to other parts of their body. Cancer that has spread to the skeletal system is the third most common type of metastases, after those occurring in the lungs and liver. These skeletal metastases commonly occur in people with lung, breast and prostate cancer. They can be painful and, if untreated, can lead to MSCC.

MSCC affects individuals physically, psychologically and socially. It can have a significant impact on quality of life and the ability to carry out normal daily living activities.

Incidence

As cancer survival rates continue to improve with advancing oncological treatments, the incidence of symptomatic MSCC is expected to increase.

Research has shown that 77% of patients diagnosed with MSCC had an established diagnosis of cancer. Conversely, 23% presented with MSCC as the first presentation of malignancy.2

The whole of the spine can be affected by MSCC, but the thoracic spine is the most commonly affected site (in about 70% of cases). This is followed by the lumbar spine and sacrum (20%) and the cervical spine (10%).3

What is MSCC?

MSCC is defined radiographically as an epidural metastatic lesion, which is causing true displacement of the spinal cord from its normal position in the spinal canal.4

It is deemed an oncological emergency due to the devastating effects it can have on people, and it is an important source of morbidity (including paralysis, and bowel and bladder disorders) in people with systemic cancer.

In 2008 the National Institute of Health and Care Excellence (NICE) published MSCC guidelines to guide healthcare professionals in providing evidence-based care for the condition.1 The guidelines state that patients with a history of cancer and recent altered neurology consistent with MSCC need to be referred to an MSCC coordinator urgently (within 24 hours).

About the author

Helen has followed a career in physiotherapy and lecturing, and has specialised in oncology working as the Therapies Manager at the Velindre Cancer Centre. She has a particular interest in MSCC. Her role combines some clinical physiotherapy with managing a team of allied health professionals, to provide an integrated approach to service delivery for patients living with the impact of cancer.
People who have cancer that has spread to their bones, or which is at risk of doing so, should be given high-quality information. This should preferably be in the form of an alert card, which explains what to do and who to contact if they develop symptoms of spinal metastases or MSCC, as recommended by the NICE guidelines.

**Signs and symptoms**

**Back pain**
Back pain is the most common presenting feature in MSCC cases, occurring in 83–95% of cases. It may be associated with referred pain to the torso or limbs. Back pain in adults is a common complaint, with most cases being benign. Therefore the challenge is to identify cases where back pain is caused by a serious spinal disease, such as malignancy. Thoracic pain is less common in the general population than pain originating from the mobile cervical and lumbar regions, and so should increase suspicion of the likelihood of cancer.5

Three classic pain syndromes affect people with spinal metastases:
1. Local pain at rest and associated with spinal tenderness, resulting from periosteal stretching from tumour growth and/or local inflammatory processes.
2. Mechanical pain on movement owing to instability (which is improved by rest).
3. Radicular pain owing to irritation of a nerve root.6 Patients will often present with a combination of these. The pain is often severe and unremitting, aggravated by straining and is present at night, preventing sleep.

**Reduced muscle power**
Although the rate of clinical progression is variable, people with reduced muscle power will inevitably progress to complete paralysis in the absence of intervention.3

Studies have consistently demonstrated that if MSCC is diagnosed late, motor function (and therefore ability to walk) at the time of MSCC diagnosis is directly associated with ability to walk after treatment. People who are unable to walk when diagnosed, who may then never recover their ability to walk, are likely to have an overall poorer prognosis. In some people, damage to the spinal cord results in significant permanent paralysis being present at the time of diagnosis.

Around 50% of people with MSCC present to health care professionals with the inability to walk, and of this proportion, 80% do not regain ambulatory function. However, of the 50% who are able to walk when they present, 80% regain ambulatory function.1 It is therefore imperative to diagnose this condition early to prevent irreversible neurological damage that can affect a patient’s mobility and function.

Furthermore, treatment before paralysis is clinically and cost effective.7

**Sensory abnormalities**
Sensory changes such as paraesthesia or anaesthesia typically occur in correlation with motor weakness. People may therefore complain of sensory abnormalities in the same dermatomal distribution as their motor dysfunction, and people with myelopathy may describe a sensory change across the chest or abdomen.

**Bladder and bowel dysfunction**
Sensory and autonomic symptoms and signs are late presentation features but 40–64% of people with MSCC may also have some degree of dysfunction of the bladder, bowel, and sexual organs. Bladder dysfunction is the most common and often correlates with the degree of motor dysfunction.5

Allied health professionals, particularly physiotherapists working in primary, secondary or tertiary care, will often be treating people with the above presentations. They are often at the forefront of responding to the ‘red flags’ and making prompt and appropriate referrals before any permanent neurological damage occurs. This ensures that steroid prescription can be commenced with prompt consideration of spinal surgery and radiotherapy.
Metastatic spinal cord compression

Investigations and diagnosis
Audits have demonstrated significant delays from the time that people first develop symptoms to recognising the possibility of MSCC. It’s important that people who have cancer which may spread to the spine are aware of the symptoms of spinal metastases and MSCC, because diagnosing the disease quickly can help to prevent spinal cord damage and disability. Therefore anyone who suspects a patient of having MSCC should immediately contact a specialist spinal or acute oncology team, so that urgent imaging and further management can be considered. The NICE guidelines recommend that centres treating people with this condition have a coordinator who advises clinicians, coordinates care, and organises urgent magnetic resonance imaging (MRI). MRI remains the optimal imaging modality for assessing spinal metastatic disease.8, 9

Management
Upon suspicion of MSCC, people should be nursed flat with the spine in neutral alignment, log rolling when required, to prevent or limit any further neurological deterioration. Definitive treatment should be started as soon as possible after diagnosis, ideally within 24 hours, with the aim of minimising permanent damage to the spinal cord. A full, clear and accurate neurological assessment should be carried out to establish a baseline against which further assessments can be made during ongoing progression of movement to sitting, standing and mobilisation.

People may have considerable pain and should receive analgesia in accordance with the World Health Organization’s ‘pain ladder’ (see opposite page).

NICE guidelines showed, on the basis of a systematic review of low-quality randomised controlled trials and observational studies, that corticosteroids (dexamethasone 16 mg daily with gastric protection) may result in rapid improvement of pain and neurological function as the shrinking of the tumour relieves pressure on neurological structures.1, 10, 11

Primary treatment depends on a patient’s performance status, prognosis, preference, and tumour histological type. In very frail, terminally ill patients, active treatment may not be appropriate. Many patients who are diagnosed late are not suitable for surgery and should receive urgent external beam radiotherapy, although systematic reviews give no clear consensus on the best radiotherapy dose and fractionation.12

People with paraplegia are unlikely to regain any function, and treatment is mainly intended to help with pain.

NICE therefore recommends surgery (decompression and stabilisation) plus radiotherapy for people who are fit enough for surgery, have a prognosis of at least three months, and where one or more of the following applies:

- spinal cord compression and have not had paraplegia for more than 48 hours
- an unstable spine
- deteriorating neurological function
- pain despite previous radiotherapy.

Chemotherapy may occasionally be used as a primary treatment for MSCC that results from chemo-sensitive disease, such as small cell lung cancer and lymphomas.

Whatever treatment a patient receives, ongoing multidisciplinary care across primary, secondary and tertiary care is crucial, attending to the person’s medical, social, and psychological needs. Assisting patients and their families to make adjustments to the changes in their lives which have occurred as a result of the MSCC is highly important. Provision of appropriate rehabilitation services, aids and adaptations, focusing on the person’s goals and desired outcomes, including functional independence, will maximise their potential to ensure they enjoy the best quality of life possible.

Specialist palliative care is also crucial, as only about a fifth of patients with MSCC will survive for more than one year.1

Managing complications such as venous thromboembolism and pressure ulcers is vital
for people whose physical function is limited due to paralysis and its resulting immobility. Management of bladder and bowel continence, and monitoring of circulatory and respiratory functioning, are also requirements to ensure appropriate care.

WHO pain ladder

**Step one**
Non-opioid
With or without other medicines

**Step two**
Weak opioid
With or without non-opioid
With or without other medicines

**Step three**
Strong opioid
With or without non-opioid
With or without other medicines

---

**References**

**MSCC services**

These accounts of services in different regions show the impact that early interventions, and the presence of dedicated coordinators, can have on outcomes for people with MSCC.

---

**Manchester**

The Manchester Cancer Metastatic Spinal Cord Compression service was launched in November 2013 and has significantly improved the care of patients who develop this devastating condition across our region (which has a population of 3.2 million).

**What we do**

The service is based at the Christie and provides a single point of contact for both primary and secondary care. It offers advice and coordinated care for people with MSCC, by following a network pathway built on evidence-based guidelines. Patients are triaged and referred for surgical opinion, radiotherapy, systemic treatment or best supportive care.

---

**Our impact**

Data is collected prospectively (from current patients). A recent user survey found very high levels of satisfaction and approval. Evaluation of the service has demonstrated a rapid increase in referrals, with over 90% of patients undergoing an MRI scan and treatment within 24 and 48 hours respectively. The surgical referrals have increased significantly and a close working relationship has been established with the specialist spinal unit.

The MSCC pathway is now streamlined and offering a consistent level of care, including rehabilitation, for all patients. It has contributed to effective lines of communication between primary and secondary care and the specialist treating centres.

Evaluation also shows that when appropriate, patients received radiotherapy within 24 hours. The numbers of patients who received surgery has trebled compared with the data prior to the launch of the service. We also run an education programme. This has increased the skills and confidence of clinicians in all settings. The MSCC pathway has now been firmly embedded within Greater Manchester and Cheshire.

---

Lena Richards
Lead Network
MSCC Coordinator
The Christie NHS Foundation Trust
0161 918 7058
lena.richards@christie.nhs.uk
RPH is the tertiary centre for oncology and neurosurgery in the region. Therefore all patients referred to the MSCC service are discussed with both teams on a daily basis. This facilitates the delivery of a high standard of holistic clinical care, involving all relevant members of the multidisciplinary team when deciding on the most appropriate management of each individual case.

Once a person is admitted or transferred for treatment at RPH, I ensure timely referral to appropriate services such as physiotherapy, occupational therapy and social work. This allows for early assessment of potential care needs on discharge. I act as the key worker for these patients during their stay at RPH, in the absence of their local site-specific specialist nurse. I can also support people who have a new diagnosis of cancer.

Our impact
In 2014, 364 patients were referred to the service with 129 (35%) confirmed MSCC cases following investigation. All patients suitable for active treatment were discussed with both neurosurgery and oncology teams, ensuring all potential treatment options were explored. Of the 129 confirmed cases, 72% had a previous diagnosis of cancer and in 28% the MSCC was the first presentation of malignancy.

My background as a cancer nurse enables me to not only coordinate care between various clinical teams, but also to offer advice, emotional and psychological support. In addition, close working relationships with the acute oncology and cancer-of-unknown-primary teams ensures these patients get appropriate support throughout.

I also play a crucial role in education, both at the trust and in the wider community. A number of teaching sessions for primary care and community physiotherapy, to highlight early detection of MSCC, have been well attended. An MSCC evening masterclass for the region is planned for autumn 2015.

Sandra Curtis
MSCC Coordinator
Lancashire Teaching Hospital NHS Foundation Trust
sandra.curtis@lthtr.nhs.uk
01772 523 204
MSCC services

West Midlands
The Spinal Oncology Service at the Royal Orthopaedic Hospital NHS Foundation Trust (ROH) covers the West Midlands for spinal metastases, and is UK-wide for primary spinal bone tumours.

The service comprises ten spinal consultants who cover on-call emergency oncology referrals 24/7. Four of the consultants have a special interest in tumours and take the urgent or on-call referrals. We have two interventional radiology consultants with a special interest in spinal oncology. They carry out CT-guided biopsies and vertebroplasties, plus musculoskeletal pathology consultants. I coordinate the service and we have an extended team across the West Midlands of oncology consultants, interventional radiologists, vascular, GI and thoracic consultants.

What we do
We manage emergency and urgent oncology referrals from Birmingham, the Black Country, Worcester and Hereford. Emergency and urgent primary bone tumours are referred from across the UK.

We have raised the profile of MSCC through local and national educational events and close working partnerships with clinicians across the West Midlands, with the aim of early referral of people with spinal metastases or primary tumours, to allow early investigation and intervention and reduce numbers of people presenting with MSCC.

Our impact
We have agreed guidelines for the referral of patients with spinal metastatic disease with pathways for emergency (MSCC) and urgent referrals. We have developed information cards for patients and carers, to help early recognition and management of signs and symptoms of MSCC. Referral numbers are increasing.

The MSCC Coordinator role is undertaken by myself in-hours, and by the on-call spinal registrar out-of-hours. This involves triage of referrals and assessment of patients, liaison with spinal and oncology consultants and acute oncology teams, coordination of patient pathway in terms of information, imaging, biopsy, admission, discharge, referrals and follow up. I also carry out telephone triage of new referrals and arrange MRI, staging scans, admission and a fast-track clinic.

We have a spinal oncology multidisciplinary team (MDT) that runs on a weekly basis. This is a diagnostic and planning team. All new referrals are discussed by the team and post-operative patients and histology results are confirmed, ensuring the patient pathway is consistent and timely. We plan the management of urgent and emergency patients every day. There is a sarcoma MDT once a week at the ROH and, in the case of primary bone and soft tissue tumours, there is close liaison with this meeting.

Nurse-led fast-track spinal oncology clinics run four days each week. People are also assessed on our spinal ward as necessary, as we have a spinal emergency bed open at all times. I assess and examine patients and have a consultation with the spinal consultant to plan surgical management. This can range from a vertebroplasty to decompression and instrumentation for spinal metastases, or complex en-bloc excisions for primary bone tumours. The clinic is run as a one-stop clinic so any investigations can be done on the day and decisions made about management.

MSCC coordination in the West Midlands has been supported and enhanced by the UK Oncology Nursing Society acute oncology group chaired by Philippa Jones, which meets every three months to work on service development and education, including MSCC.
so close, he needed to have a procedure to reduce the blood supply to the cancer or he could bleed out. All the difficulties that could happen were carefully explained. Mr Stirling said that he felt the operation could give John a better quality of life, but that chemo would not be able to take place for a time afterwards, as it would impede the healing.

We were left to discuss whether to accept the operation, with the chance that John’s life would be shortened due to the postponement of the chemo, or to not have the op and risk him becoming paralysed due to the invasion of the cancer into his spinal cord. We had always agreed that quality of life was more important than quantity, so we accepted the option of surgery and John had the operation on 23 July 2014.

The pain in his legs went as soon as he came round from the operation. The care and consideration he had was excellent. The consultant came to see him and was pleased with the results. He told us that, while doing the procedure, he was able to reduce the cancer and divert it from the spine. The consultant told us that, had John not opted for this, he would have been paralysed in a matter of weeks. So we felt we had completely made the right decision to go ahead.

John unfortunately died on 18 February 2015, but his last months were without pain and he was able to be mobile and have a reasonable quality of life. We were even able to go away on a holiday to the Isle of Wight in September, which we would not have been able to do if he had not had it done. With all the treatment he had and the procedures and follow-up appointments, we always felt treated well and kept well informed and cared for.

I will always be grateful for the treatment he had as it gave us seven months of quality life together which we would not have had if he had not had the operation.

John’s story
My husband John was diagnosed with a rare cancer in January 2013. He had a course of chemotherapy in March 2013 and radiotherapy the following December and January. But he started having pain in his legs in February 2014, and it was found that the cancer had spread to his spine.

He was referred to the Royal Orthopaedic Hospital (ROH) in June 2014 where he saw a consultant and Anita Killingworth, who was incredibly helpful and explained everything in an understandable way.

John was by this time having great difficulty walking and was due to have a further course of chemo in July. Meanwhile he had been treated for high calcium levels due to the invasion of his bone by the cancer. He was admitted to Heartlands Hospital to have this treated and therefore missed the start date of his chemo.

He was sent an appointment at the ROH for 21 July 2014 to see a consultant and was in so much pain by now that he could not walk or sit comfortably. The nurse in charge of the ward saw his discomfort and arranged for him to be in a consulting room where he could lie flat which was much better. The consultant and his registrar came to speak to us and explained in great detail that it would be possible through an operation to implant some bone in John’s vertebra and fuse some of the others together. But due to the cancer being
MSCC services

Stoke-on-Trent
Prior to becoming the Royal Stoke University Hospital, the previously named University Hospital of North Staffordshire responded to the NICE guidelines 2008 and, following a period of consultation, commenced the MSCC coordinator service in 2011.

The trust serves a population of approximately 700,000 people living in and around Staffordshire and beyond. The Royal Stoke University Hospital provides specialised services, such as trauma (for three million people in a wider area, including neighbouring counties and North Wales), cardiac and cardiothoracic surgery, spinal surgery, neurosurgery and cancer.

What we do
Surgery for spinal metastases and MSCC is undertaken by the spinal surgical team who provide a 24/7 service. Radiotherapy is provided on-site by the cancer centre, which provides highly specialised treatment to a population of approximately 1.2 million people.

The MSCC service at the Royal Stoke is coordinated by the Clinical Nurse Specialist (CNS) for Malignant Bone Disease between 8am and 4pm Monday to Friday and out-of-hours by the Spinal Registrar on call. It provides a point of contact for all emergency portals, in-patient wards, other teams within the Royal Stoke, community teams and other hospital trusts.

This service provides advice to professionals, coordination of investigations and swift process through the pathway to treatment (where appropriate) for patients referred with suspected MSCC and spinal metastases. The Coordinator aids communication between all trust departments ensuring that clinicians have access to all relevant clinical information including imported images. She also supports patients and carers throughout.

Given the wide variety of services provided by the trust, many people present with MSCC or spinal metastases as their first indication of cancer. On these occasions the CNS acts as key worker ensuring that correct pathways are followed through to diagnosis of their cancer, treatment for their spinal disease and that the patient and family are supported and informed.

Our impact
There has been considerable positive feedback for this service from patients, carers and other health care professionals including those from outside the trust. On one particular occasion, a patient was referred by a GP following a routine MRI scan for back pain which had shown spinal metastases. The patient was admitted, diagnosed with prostate cancer, had spinal surgery, and was seen by the prostate cancer team all within seven days. Feedback was that both the GP and the patient were impressed and that the patient felt supported throughout.

The CNS regularly attends the Macmillan Acute Oncology Nurses Forum and West Midlands Strategic Clinical Network Acute Oncology, MSCC and CUP Expert Advisory Group and is constantly looking to improve outcomes for this group of people on a regional and national level.

Andrea Chatterley
Macmillan Nurse
Specialist Malignant Bone Disease
University Hospitals of North Midlands NHS Trust
01782 675 278
andrea.chatterley@uhns.nhs.uk
South Wales Cancer Network
The Macmillan and South Wales Cancer Network Project began in October 2013 with funding for two years. The two broad aims of the project are:

• To develop a long-term strategy to standardise the management and care of MSCC patients, and implement this strategy across South Wales. The region consists of six Health Boards and Velindre NHS Trust, serving a population of 2.3 million.
• To deliver a standardised education package for all health care professionals.
• To provide evidence to demonstrate the need for MSCC coordinators across South Wales.

The aims and objectives of the project are in line with the 2008 NICE guidance on MSCC, Macmillan’s Value Based Standards, and all of Macmillan’s strategic goals around the long-term consequences of cancer and its treatment.

In addition, the project will have a positive impact on the lives of people affected by cancer by implementing best practice and person-centred care.

The project will be leading the way forward within primary and secondary care in aiding all people in South Wales to access the best possible treatment for MSCC, and therefore maintaining mobility by giving timely access to support.

The project is currently driven by four working groups: Education & Information, Radiology, Rehabilitation, and Surgery. The groups have representation from each Health Board across South Wales, enabling dissemination of information. Each group has its own working agenda which will contribute to the development of the South Wales MSCC strategy.

Kate Baker and Kathryn Elias (pictured above)
Macmillan MSCC Service Improvement Leads, South Wales Cancer Network
kate.baker@wales.nhs.uk
kathryn.elias2@wales.nhs.uk
01792 530 845
Gavin’s story

My problems started in September 2014 when I noticed a lump in my groin. Apart from a few back pains, which were not unusual for me, I felt fine. My GP referred me to a consultant who, after conducting various tests, concluded it was nothing of concern and was not cancer. Over this same period, I started having pains in my lower back and further tests did not really identify the problem. Eventually, a few days before Christmas that year, I started feeling some numbness in my legs which progressively worsened over the next few days. I was referred to A&E for a suspected spinal compression problem.

After further tests, it was confirmed as metastatic cancer of the spine, having likely originated from prostate cancer. Perhaps understandably, this came as a massive shock. I was admitted to hospital immediately for an urgent spinal decompression operation.

Before the operation, Sandra Curtis, an MSCC Coordinator (see page vii), introduced herself and the type of help she could provide if needed. Sandra provided a lot of relevant information including various cancer booklets, fact sheets and available support groups. As well as supporting me, Sandra also helped support my wife during this difficult time. She also informed us of the help we could get with prescription charges, parking at the hospital site and other such logistical issues. If there were questions that Sandra could not answer, she always found out from the relevant staff, doctors or consultants.

I found it particularly useful to have Sandra there to explain, in clear and empathic terms, my diagnosis and its impact when my family was present. Due to the upsetting nature for all concerned, I am not sure I could have done that myself.

Sandra also visited me on the day of my back operation to see if I was okay, or had any worries or concerns.

When being treated for multiple aspects of the condition, along with initial and ongoing cancer treatment, I don’t think it is always clear from a patient’s perspective as to who is managing their condition as a whole. As MSCC Coordinator, Sandra’s role helps bridge that apparent gap, finding out information if needed, making things happen when they seem to have been forgotten, and finding out specific answers from consultants without having to make appointments to see them, which would otherwise be time-consuming and slow for all concerned.
Scotland
The diagnosis, management and outcomes of MSCC in Scotland were audited by the Clinical Research Audit Group (CRAG) in 1997. This prospective audit reported that there were three key reasons for delays in MSCC diagnosis:
• failure to recognise early symptoms
• failure to undertake appropriate investigation
• lack of referral pathways.

The report recommended that cancer networks should develop strategies aimed at improving outcomes for people with MSCC through earlier diagnosis.
Following funding from Macmillan, NHS Scotland’s three regional cancer networks collaborated to develop in the following areas:

Developing guidance
In addition to the West of Scotland’s MSCC guidelines, available at tinyurl.com/ws-mscc, each network now has locally agreed referral pathways for people with suspected MSCC. The pathways promote local investigation with prompt transfer to a specialist treatment centre, where MSCC guidance promotes consistent management.

Promoting education for professionals
A variety of educational resources are now available to support those delivering MSCC education in Scotland. The networks have developed a core MSCC presentation and an MSCC quiz. There is a Macmillan MSCC toolkit DVD, designed for professionals in Scotland and produced as part of a Scotland-wide programme in conjunction with cancer networks, which is available at learnzone.macmillan.org.uk.

Giving patients information
The West of Scotland’s MSCC patient information for people with an MSCC diagnosis helped to inform the information currently available on the Macmillan website about MSCC. This is used to support patient discussion. Patients in the West of Scotland considered at risk of developing MSCC also receive an alert card with the signs and symptoms of what to look out for, as well as information for professionals on action to take.

The South East of Scotland Cancer Network (SCAN) developed the leaflet ‘Bone Problems and Back Pain in People with Cancer’ to support people with either suspected or diagnosed MSCC. This is available at scan.scot.nhs.uk.

Developing a dataset
Following implementation of new initiatives, a dataset was developed to audit presenting symptoms, referral, investigation, management and follow-up of people with MSCC. Outcomes from the 12-month prospective audit reported improvements when compared with the original CRAG audit, including a reduction in time of referral to investigation and better mobility at time of diagnosis.

Conclusion
In Scotland, patients with suspected MSCC are investigated locally and are only transferred to their nearest treatment centre following positive MRI. This translates to a better experience for patients, better use of resources and an overall more efficient service. In turn, early diagnosis means a greater chance of remaining mobile through earlier recognition, investigation and treatment.

Lessons learnt have been shared with a variety of healthcare professionals locally, nationally and internationally, and were influential in the development of the NICE MSCC guidance.

Jackie Whigham
Acute Oncology Project Manager
Edinburgh Cancer Centre
jackie.whigham@nhslothian.scot.nhs.uk

Dr Cathy Hutchison
Cancer Consultant Nurse
Beatson West of Scotland Cancer Centre
cathy.hutchison@ggc.scot.nhs.uk
Northern Ireland Cancer Network

In 2011, the Northern Ireland Cancer Network (NICaN) MSCC project began with the appointment of a full-time Project Manager for three years. The aim of the project was to implement the NICE Guidelines for the diagnosis and management of adults with, and at risk of, MSCC in Northern Ireland.

Northern Ireland has five Health and Social Care Trusts with 10 acute hospitals, for a population of 1.8 million. Oncology provision is via the Cancer Centre in Belfast Trust, where systemic anti-cancer therapy (SACT) and radiotherapy are delivered. The four other trusts each have a cancer unit delivering SACT regimens. Spinal surgery is performed in the Royal Victoria Hospital, Belfast.

The overall objective of the project was to improve the quality of care provided to adults with and at risk of MSCC in Northern Ireland by ensuring the effective configuration, co-ordination and availability of services required to meet the standards outlined in the NICE Guidelines.

Objectives of the project

The specific objectives of the project were to ensure the following:

• Appropriate services are commissioned and in place for the efficient and effective diagnosis, treatment, rehabilitation and ongoing care of patients with MSCC.
• These services are monitored regularly through prospective audit of the care pathway.
• People who are at high risk of developing metastases, who have diagnosed bone metastases, or who live with cancer and present with spinal pain are informed about the symptoms of MSCC – along with their families and carers.
• People with signs and symptoms suggestive of MSCC are cared for in a timely and coordinated fashion, including access to 24-hour clinical advice, imaging and treatment.
• Effective discharge planning and ongoing care of patients diagnosed with MSCC, including rehabilitation and community support services.

Outcomes

• Regional pathways were developed and agreed. These pathways are the baseline for each trust to develop their own local pathways.
• An electronic referral form was developed, for use regionally to refer people to the spinal surgical team and the on-call oncology registrars.
• A patient information leaflet, informing patients and carers of the signs and symptoms of MSCC, was developed and published. This is now available in all oncology clinics for clinicians and nursing staff to use when appropriate.
• Access to out-of-hours MRI has improved.
• A quarterly update of MRI services across the region is supplied to all trusts.

The MSCC project finished in September 2014, as funding has been secured in Northern Ireland regionally for an Acute Oncology Service, which is to be implemented this year. With this service, an Acute Oncology Clinical Reference group will be established, which will incorporate the ongoing work of MSCC.

Clodagh O’Brien
Former Macmillan MSCC Project Manager
NICaN
clodagh.obrien@northerntrust.hscni.net
028 9442 4588

Deborah Kerr
Macmillan Service Improvement Lead for Oncology
NICaN
deborah.kerr@hscni.net
07747481235
Policy

England
Support for Commissioning Metastatic Spinal Cord Compression
This 2014 NICE document highlights the key actions that NHS England and Clinical Commissioning Groups (CCGs), and their partners, should take to improve the quality of care for people with MSCC.

This document recognises that CCGs and NHS England, as the two bodies responsible for commissioning the various services in the care pathway related to MSCC, should work collaboratively to integrate care pathways. This is in respect to providing information about recognising symptoms; ensuring protocols are in place to secure supportive care and rehabilitation; and ensuring adults with MSCC, who present with neurological symptoms or signs, start definitive treatment within 24 hours of a confirmed diagnosis.

This document also states that NHS England and CCGs should work together to ensure timely imaging, definitive treatment plans and coordinated investigations – through providing access to an MSCC coordinator.

Scotland
Better Cancer Care
This 2008 plan aims to spell out the actions required to support all those in Scotland living with and beyond cancer. It confirms that cancer remains a national clinical priority for NHS Scotland and looks to partnerships with a range of stakeholders to improve outcomes for everyone affected by cancer.

The plan addresses prevention, early detection, genetic and molecular testing, referral and diagnosis, treatment, living with cancer, improving outcomes, and quality. A 2009 progress report on the plan acknowledged the need for reviewing and planning acute oncology services, which are a key first point of contact for MSCC cases.

Wales
Together For Health – Cancer Delivery Plan
This 2012 plan sets out the Welsh Government’s expectations of the NHS in Wales to tackle cancer. It provides a framework for action by local health boards and NHS trusts. The plan is designed to enable the NHS to deliver on its responsibility to meet the needs of people at risk of cancer or affected by cancer.

The plan recommends that local health boards need to plan and deliver coordinated services for people with MSCC and measure outcomes. It states that they are expected to plan acute oncology services to deal with issues such as MSCC, in line with guidance from NICE and NCEPOD (National Confidential Enquiry into Patient Outcomes and Death).

The plan also states local health boards are expected to place more emphasis on the needs and experience of people with MSCC.

Spinal surgeons and oncologists.

Download at tinyurl.com/spinal-taskforce

Commissioning Spinal Services
This 2013 guide lays down the National Spinal Taskforce’s recommendations for both commissioners and providers of spinal services. A key recommendation is that all commissioners of spinal services should ensure comprehensive spinal networks are established to facilitate integrated pathways. It also recommends that all providers of spinal services (irrespective of whether they are commissioned at CCG or specialist commissioning level) should be subject to the same clinical governance arrangements.

The Taskforce state that commissioners should review provision of services to manage MSCC. This is particularly in respect to the geographical coordination of appropriate imaging, and reviewing the provision of on-call spinal surgeons and oncologists.

Download at tinyurl.com/nice-mscc
Macmillan response to Cancer Delivery Plan
The National Assembly for Wales’ Health and Social Care Committee is currently undertaking an inquiry into progress on implementing the Welsh Government’s Cancer Delivery Plan. This includes a recent consultation, to which the Macmillan MSCC Service Improvement Lead for the South Wales Cancer Network responded. The response recommends that dedicated MSCC coordinators are provided in each cancer centre, and that a strategic approach to cancer patient information is provided, to ensure patients know what to do and who to contact if they develop symptoms of MSCC.

The response also recommends a long-term strategy is produced in Wales to standardise the management and care of MSCC patients, and that the Welsh Government works with local health boards to develop a standardised education package for all healthcare professionals in Wales to use.

Download at tinyurl.com/mac-cdc-response

Northern Ireland
Guidelines for the Rehabilitation of Patients with Metastatic Spinal Cord Compression
This 2014 document, produced by GAIN (Guidelines and Audit Implementation Network), was developed with the Northern Ireland Cancer Network (NICaN) MSCC Allied Health Professional sub-group. It was part of a wider multidisciplinary review of the regional management of MSCC in Northern Ireland (by NICaN), in keeping with the UK-wide NICE guidelines on MSCC. It provides guidance on physiotherapy and occupational therapy for people with MSCC.

Download at tinyurl.com/gain-mscc

Coming soon: Macmillan MSCC alert card
Macmillan is currently developing a free, Macmillan-branded patient alert card with information about the symptoms of MSCC. This will be a resource that can be given out by professionals across the UK. This resource should be available from September – please look out for more about this in future issues of Mac Voice.