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

Malignant Spinal Cord Compression (MSCC): Patient and Carer Information

Version Control

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

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Version	Date Issued	Review Date	Brief Summary of Change	Owner's Name
1.0	August 2012	August 2015	Original Document	AOCEG / MSCC CEG / Physiotherapy Department HEYHT
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2.0	January 2016	January 2018	Review and update to HEY Acute Oncology Group	HEY Acute Oncology Group
3.0	May 2019	May 2021	Update	AOG

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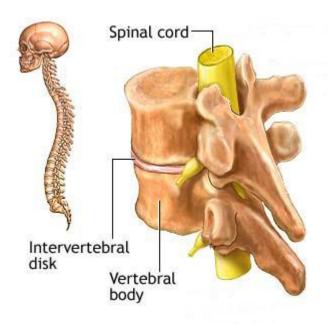
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Introduction

This leaflet has been produced to give you general information about your condition. Most of your questions should have been answered by this leaflet. It is not intended to replace the discussion between you and your doctor, but may act as a starting point for discussion. If after reading it you have any concerns or require further explanation; please discuss this with a member of the healthcare team caring for you.

What is Malignant Spinal Cord Compression (MSCC)?

The spinal cord is a large bundle of nerves that runs down the length of the spine. The spine is made up of individual bones called vertebrae which help to keep the body upright and protect the spinal cord. As the spinal cord passes through each bone it gives off smaller nerves called nerve roots. These supply the trunk, arms and legs with sensation (feeling) and control of muscles. The spinal cord carries messages between the brain and the rest of the body.



Copyright: www.sci-recovery.org/images/vertebraeandspinalcord.jpg

Spinal cord compression is due to pressure on the spinal cord and its nerves. This results in swelling and a reduction in the blood supply to the spinal cord and nerve roots. This can be due to the bones being affected by cancer causing them to weaken, the cancer spreading into the tissues around the spine or the cancer affecting the spinal cord itself.

Spinal cord compression can be caused by a primary tumour (original tumour) or due to secondary spread from metastases (spread of the tumour to other parts of the body away from the original site), most commonly it is due to metastases.

Spinal cord compression is more commonly seen in people with cancer affecting the breast, lung, or prostate and in people who have lymphoma or myeloma.

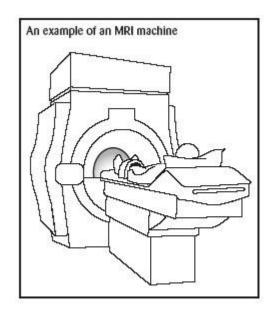
What symptoms will I have?

This depends on the part of the spinal cord affected by the tumour

- Unexplained pain in the neck or back, may feel like a 'band', sometimes
 described as burning or shooting, can spread (radiate) around the side of the
 body or down the arms or legs
- Numbness, tingling or pins and needles in the arms or legs
- Loss of control of the bowel and bladder (constipation, problems passing urine)
- Weakness in the arms or legs
- Feeling unsteady on your feet, difficulty walking, or your legs giving way

How is Malignant Spinal Cord Compression diagnosed?

Usually a MRI (Magnetic Resonance Imaging) scan is carried out. This involves lying on a couch inside a long tube for about 30 minutes and magnetism is used to build up a detailed picture of areas of your body. It is not painful but some people can feel a bit claustrophobic and it is noisy. Pain relief (analgesia) may be given before this procedure if you find it uncomfortable to lay flat.



Sometimes you have a CT (Computerised Tomography) scan, this takes a series of x-rays to build up a 3D picture of the inside of your body or you can have an x-ray taken.

Bone scans can check if there are any abnormal areas in the bone. They cannot diagnose MSCC.

What medical treatment will I have?

Treatment should be started as soon as possible after diagnosis, in order to prevent permanent damage to the spinal cord, which can lead to serious disability including paralysis (inability to move or feel)

The choice of treatment depends on several factors, including the type and stage of cancer, the area affected, any previous treatment and your general health and fitness.

Your healthcare team will discuss your treatment options, giving you details about the possible benefits and risks of particular treatments and involving you in all decisions about your treatment and care. You can ask any questions you wish and can change your mind as your treatment progresses or your condition or circumstances change.

Bed rest

You may be asked to stay in bed, lying as flat as possible, this is the safest and most supportive position for your spine. You may need to wear a supportive collar if your neck is affected. If your doctor considers your spine to be stable you will be able to sit up, if this causes discomfort please inform the doctor or nurse immediately.

Supportive care

The nursing team will help assist with personal care, such as washing and toileting. Sometimes a urinary catheter is needed to help empty your bladder or medicines may be offered to improve bowel function. They will also help to keep you comfortable in bed and assist you with meals if needed.

If you are having surgery or are unable to move around you are at risk of developing a blood clot, you may be given compression stockings and medicines that help to reduce the risk of blood clotting (anti-coagulants)

If you are unable to move around you are at risk of developing a pressure ulcer. You may be offered a pressure mattress or cushion and encouraged/helped to change position and participate in gentle exercises/movement.

Pain Relief

Medicines will be given to help relieve the pain.

Steroids

Steroids (dexamethasone) are usually given to reduce the swelling around the nerves, they are gradually reduced over time.

Surgery

Sometimes surgery may be considered for a small number of people as part of their treatment. This will be discussed with you and you will need to be transferred to another hospital under the care of a neurosurgeon. The aim of surgery is to remove as much of the tumour as possible to relieve pressure, this may involve removing several parts of the bones that make up the spine. Treatment may involve injections of a special bone cement into the spine to help ease the pain and strengthen the spine.

Radiotherapy

Radiotherapy is the usual treatment for MSCC. High energy x-rays are used to reduce the size of the tumour, thereby reducing pressure on the spinal cord. This treatment cannot completely remove the tumour and cannot achieve cure, but aims to improve symptoms of pain and can sometimes stop the weakness developing

further. Unfortunately there is not a good result in all cases, especially if the nerve damage is severe with marked functional loss.

Radiotherapy usually involves 1-10 daily treatment sessions and can take several weeks to fully take affect. The return of some strength or sensation in the first week is an encouraging sign. No change in the first week means that recovery is unlikely.

Radiotherapy involves using a machine called a simulator to assist in accurately marking on your body where the radiotherapy needs to be delivered. You have to lie on your back and have x-rays and measurements taken. A different machine called a linear accelerator is used to deliver the radiotherapy treatment, this again involves lying still on a firm couch for a few minutes whist the treatment is delivered.



Image taken from the Radiotherapy Department at the Queen's Centre for Oncology and Haematology, Castle Hill Hospital

Are there any side effects to treatment?

Sometimes radiotherapy treatment can cause side effects and this depends on the area treated.

Sometimes treatment can cause nausea and sickness, this can often be prevented by taking an anti-sickness tablet. Treatment to the upper spine (chest area) may cause

temporary soreness of the gullet or a sore throat if the neck is treated. Some people can feel tired (fatigued) during and after their treatment.

Chemotherapy

Chemotherapy is occasionally used to treat spinal cord compression. It may be used for tumours that are sensitive to chemotherapy such as lymphoma and small cell lung cancer. It uses anti-cancer (cytotoxic) drugs to destroy cancer cells.

Biphosphonates

These medicines help to relieve pain and protect the bones in your spine.

Hormone therapy

Hormone therapy is sometimes used in combination with other treatments such as chemotherapy. This may be used for MSCC due to breast and prostate cancer.

What happens if I do not have any treatment?

If left untreated spinal cord compression would lead to permanent damage and paralysis, so it is important that it recognised and treated promptly.

Who may be involved with my care?

- The Medical Team
- The Nursing Team
- Radiotherapy Department
- Physiotherapist
- Occupational Therapist
- Social Worker
- Specialist Nurse
- Psychological and Spiritual Support Services

The healthcare team are there to support both you and your family/carers to adapt to your individual situation. They can provide information and advice. The healthcare team aims to work with you to retain as much of your independence as possible, considering your individual wishes and needs. Information on how to access psychological and spiritual support will be offered if you or your family/carers need it.

What can I expect after my treatment has finished?

MSCC affects each person differently, some patients may be able to walk without assistance but for others they may continue to have reduced function and require a walking aid or wheelchair to keep their independence. The healthcare team will work with you and your family to organise a plan of care and rehabilitation to suit your needs.

The medical team and physiotherapist will assess you and decide when it is safe for you to start to sit up/get out of bed. This will be done carefully and gradually, closely monitoring for any signs of nerve symptoms, such as altered sensation and weakness or any increase in pain.

Sometimes it is necessary for patients to move from the cancer centre back to their local hospital to continue rehabilitation. This also makes it easier to plan for any support or equipment which may be needed on discharge.

The physiotherapist and occupational therapist (OT) will assess your function. They will provide advice and support to deal with any functional change affecting your ability to carry out daily tasks and activities with the aim to maximise your potential and help you adapt to your situation. They will also help to support you, your family members and carers when planning for your discharge from hospital.

The physiotherapist will teach you exercises to help build strength and prevent joint and muscle stiffness. They will also encourage breathing exercises to keep your lungs healthy and prevent chest infections.

Both the occupational therapist and physiotherapist will advise on any equipment that might be needed to help you with activities and to become mobile. These will depend on the amount of normal function that is present. The occupational therapist will work with you with regards to your daily tasks and roles. The OT may carry out an access visit to your home to look at your living environment and give advice on any equipment or adaptations that may be helpful to make it easier for you for the immediate or longer term future.

Some people may be offered further specialist rehabilitation if it is possible to make further improvements in mobility and function, this may be provided within their own home or at a rehabilitation unit, or on a rehabilitation ward. Not all people benefit from this, but instead would be assisted to improve their quality of life through adaptation to functional tasks as above

The social worker may be involved with your care if you need to discuss having additional care support at home or are considering ongoing care in a residential or nursing home, they can also advise on any benefits you are entitled to e.g disability living allowance, attendance allowance, carers allowance, car badge scheme.

The nurses and therapists will provide support and training for families and carers so that they can feel confident in supporting you once you are discharged from hospital, including use of any necessary equipment.

If you are returning home community based support will be offered, this may include nursing care, therapy and palliative care (such as support from Macmillan, District nursing, Marie Currie, Specialist Palliative teams or the Hospice). Palliative care involves treatments for pain relief, and practical and emotional support to help manage your condition.

Could Malignant Spinal Cord Compression happen again?

Unfortunately in some people MSCC can come back, sometimes a different part of the spine can be affected. Contact your GP if any of the symptoms listed return or worsen

Glossary

- Analgesia = Pain relief medication
- Anti-Coagulants = Medicines that help to reduce the risk of blood clotting
- Bone scans = scans that check if there are abnormal areas in the bone
- Chemotherapy/ Cytotoxic Drugs = Anti-cancer medication that destroys cancer cells
- CT = Computerised Tomography, scan that takes a series of x-rays to build up a 3D picture of the inside of your body
- Fatigue = Extreme tiredness
- Linear Accelerator = The machine used to deliver the radiotherapy
- Metastases = Spread of the tumour to other parts of the body away from the original site
- MRI = Magnetic Resonance Imaging, scan that uses magnetism to build up a detailed picture of areas of your body
- Nerve roots = Smaller nerves that come off the spinal cord at the level of each spinal bone
- Paralysis = Inability to move or feel
- Pressure ulcer = Skin sore that develops due to prolonged pressure on a body area
- Primary Tumour = Original Tumour
- Radiate = Spread
- Radiotherapy = High energy x-rays used to reduce the size of the tumour
- Sensation = Feeling
- Simulator = A machine that assists the team to accurately mark on your body where the radiotherapy needs to be delivered
- Spinal cord = Large bundle of nerves that runs from the brain down the length of the spine
- Steroids = Medicines that help to reduce swelling around the nerves
- Urinary catheter = Small tube inserted into the bladder to help it empty. Urine collected into a bag.
- Vertebrae = Individual bones that make up the spine

Further information/advice

Macmillan/Cancerbackup <u>www.macmillan.org.uk</u> 0808 808 2020 Brain and Spine Foundation <u>www.brainandspine.org.uk</u> 0808 808 1000 NICE guidance <u>www.nice.org.uk</u> NICE publications 0845 003 7783

General Advice and Consent

Most of your questions should have been answered by this leaflet, but remember that this is only a starting point for discussion with your doctor. You will be asked to sign a consent form and you should be satisfied that you have received enough information before going ahead.

Consent to Treatment

Before any doctor, nurse or therapist examines or treats you, they must seek your consent or permission. In order to make a decision, you need to have information from health professionals about the treatment or investigation which is being offered to you. You should always ask them more questions if you do not understand or if you want more information.

For MSCC you will be given both verbal and written information and after having time to ask questions, you will be asked to sign a consent form to show you have received enough information and you understand it. The information you receive should be about your condition, the alternatives available to you, and whether it carries risks as well as the benefits. What is important is that your consent is genuine or *valid*. That means:

- you must be able to give your consent
- you must be given enough information to enable you to make a decision
- you must be acting under your own free will and not under the strong influence of another person

How much do I need to know?

Some people want to know as much as possible about their condition and possible treatments; others prefer to leave decisions to the experts. No one providing healthcare will force information on you, for example, about the risks of treatment if you don't want to know. But remember, the person in the best position to know what matters most is you.