

Malignant Spinal Cord Compression (MSCC) treatment: What now?

This leaflet is for patients, family and friends of patients who have been diagnosed with an MSCC. The leaflet will answer some key questions relevant to living with an MSCC.

Patient information leaflet

If you require a translation or an alternative format of this leaflet please ask for assistance.

Safe & compassionate care,
every time

This leaflet is for anyone who has completed treatment for a Malignant Spinal Cord Compression (MSCC).

MSCC often comes on suddenly and requires urgent treatment. Your treating team will give you advice about medical follow-up relevant to you. However, for many people preparing to leave hospital it can be hard to know what to expect.

In this leaflet, we have tried to answer some of the most frequently asked questions. **Please feel free to share this leaflet with your family/ carers/ friends who support you.**

You've completed your treatment – what now?

Will I be able to go home?

- You may go home independently or with the support of carers. Some patients find they are better suited to a community hospital, nursing home or hospice to ensure all their rehabilitation and care needs can be met when discharged from hospital. You will make decisions about this with your family and ward team.
- Before you leave hospital your physiotherapist or a member of the Acute Oncology team will talk to you about how to manage transition from hospital so that we know what is important to you.

I'm scared about damaging my spine again, what can I do?

- It is understandable to be worried about starting to do more again, however, you will be given individual, specific advice on what you can and can not do to keep your spine safe and stable. If approved by your doctor, getting moving as soon as possible is proven to have large benefits for health, pain and emotional wellbeing.

Adapting to changes in mobility

Will I always need to wear a brace?

- This will depend on the reason the brace was fitted. If you are wearing the brace to help with your pain, it may be that over time, and with appropriate analgesia and other strategies, you will no longer require the brace.
- If you are wearing a brace because your spine is still unstable (that means the bones are weak and are at risk of damage without extra support), it is likely that the brace will be recommended long term.

How will wearing a brace impact my daily life?

- If you have to wear a brace it may feel difficult to carry on doing the things that you enjoy. However, providing your spine is well supported (and your skin is healthy) there is no reason that you should not keep gently active. In terms of psychological well-being it is really important to keep doing things that matter to you. Speak to your physiotherapist if you have more questions.

I am worried about coping at home, what should I do?

- It is natural to be cautious as you may be going home less mobile than you were before. There is lots of practical help available and your team will discuss any new needs with you. If any new needs are well managed you should be able to cope well at home with the appropriate support.
- You may find that you need extra help, either care and/or equipment at home. Some of this might be temporary or you might need help for longer. The occupational therapy team can help adapt your home to make everyday tasks easier.

Adapting to changes in mobility

Most people see an improvement in their mobility after treatment. It is not uncommon for people to need a bit more help than before, perhaps using mobility aids, whether that is a frame or a wheelchair.

Does this mean I will not walk again?

- In some cases, this may mean not walking again. But if this is the case your physiotherapist will discuss this with you. Even if you can not walk it is really important that you are still as active as possible, and this would be the main goal.

Is it unusual to feel uncomfortable about using a wheelchair?

- Some people find using a wheelchair hard, partly because becoming disabled can bring up all sorts of thoughts and feelings. It is important to recognise what your assumptions are about using a wheelchair – it is really important to get good quality information to help you adapt to any changes.

Why would I want to use a wheelchair if I can walk with an aid?

- For some people where walking is possible it may have costs in terms of pain, fatigue and risk of falls. It is important to consider if a wheelchair may enable you to be more independent and get around so that you can continue doing the things you enjoy

How can physiotherapy help?

- A physiotherapist can help get you moving again. They can help you stay fit (maintain muscle mass) and improve your strength as much as possible. They will provide a program of exercises tailored to you and your needs and advice about braces and equipment. Talking and working with your physiotherapist is really important for your general health to help you cope with the cancer and MSCC.

Keeping active

Can I still be active?

- It is important to remain active for both your physical and mental health. The kind of activities that are right for you depend on your ability level and also which activities appeal to you.

What should I be doing?

- You should still be aiming to complete regular aerobic exercise which raises your heart rate and causes you to break a sweat. It is also important to complete muscle strengthening exercises, which may help with your activities of daily life.

What type of exercises are available to me?

- You may like to try standing or seated exercises, swimming, wheelchair exercises, adapted rowing machines or other wheelchair activities.

How do I start?

- If you are worried or have any concerns about how to start exercising more, please talk to the acute oncology physiotherapy team, who can guide you on what activities may be suitable for you.

Coping with changes to your bladder and bowels

Why does a malignant spinal cord compression affect my bladder or bowels?

- Your bladder and bowels are controlled by your nervous system. When your spinal cord is damaged, the nerves that control your bladder and bowels may also be damaged, which can result in altered function.

Will my bowels go back to normal?

- If your bowels have been affected by nerve damage as result of the MSCC you may continue to require support to be continent – most usually through developing a regular routine to empty your bowels, perhaps needing medication or practical help.
- Changes are especially likely to occur once you leave hospital, due to changes to your daily routine and eating habits. Any changes should be reported to your GP or Cancer Nurse Specialist, who will be able to provide you with advice and support to help manage these changes. Its really important that your bowels are managed so you can be active without fear of having accidents.

Will I always need a catheter?

- Many people will go home with a permanent catheter. Most people do not want to have a catheter but it may be the only way to stay dry and avoid infection.
- Living with a catheter should not have an impact on your daily activities – there all sorts of catheters. Many catheter bags can be hidden.
In the community there is a continence advisor who will be able to help provide additional advice and support to help you manage your catheter at home. Contact the Bucks Continence Triage team on 01296 566144 / 01296 318648.

Worries about another MSCC

Is it possible to have another MSCC occur?

- Unfortunately, in some people MSCC can reoccur – this may be at the same or a different part of the spine.
- You are at a higher risk of having another MSCC if you have additional metastases in/ around other areas of your spine, however your team will monitor these closely for any changes.
- You should discuss your individual risk with an acute oncology nurse, cancer nurse specialist or your oncologist.

Are the signs and symptoms likely to be the same again?

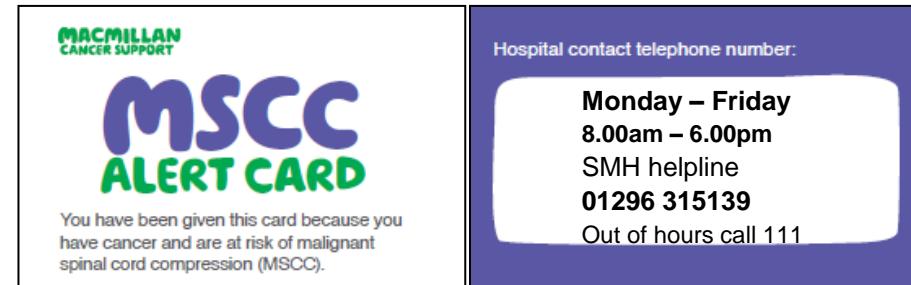
- Another MSCC may present very differently to your first. It is therefore important to be alert to all the different kinds of signs and symptoms that may occur. These can be found on your Macmillan MSCC alert card.

If I have cancer in my spine does this mean it will spread to my brain?

- Evidence does not suggest that cancer in your spine is more likely to spread to your brain.

What should I do if I have any of the signs or symptoms?

- You should immediately report any of the signs and symptoms to the Acute Oncology Triage line.]
- The sooner MSCC is diagnosed, the sooner treatment can begin to prevent permanent damage.
- Always carry your MSCC alert card with the number to call on it. You can show this to healthcare professionals, your GP and especially if you go to A&E.



Looking after yourself

How will my MSCC affect my life?

- The experience of having cancer is very challenging. It can be uncertain and requires lots of adjustments and changes. MSCC can cause disruption if it affects your mobility and bladder and bowels. Getting information and support is important.

How can I manage my pain?

- It may not be possible to be pain free but your team are here to help you to manage the pain so that you can get on with what you want to do. Pain can cause a lot of distress and interfere with getting on with day to day living, it can affect your mood, sleep, activities and relationships with others. It is important to get help to manage the pain.
- If your pain is not well managed using analgesia (medication), there are a large range of complementary therapies and other pain management strategies available to you – please ask your physiotherapist or clinical nurse specialist.

How will I cope with needing help from others?

- Requiring care from others will mean an adjustment. It is important to establish your care needs and expectations, and understand that these needs may change over time.
- Consider getting help if it will actually allow you to do more. For example, if you spend all your energy on getting dressed and washed in the morning, what else will you not be able to do? If you accept help, does it save time, pain and allow you to save your energy to do things that are more important to you?

Quality of life

How will my family manage the new demands placed on them?

- Your family may also need time to adjust to your diagnosis. There is support available for you and your family, including carer benefits, support groups and respite care. Please ask one of us for more information. Macmillan Citizens Advice can help with all sorts of financial issues, you can contact them on 01908 545160

How may I expect to feel after being diagnosed with MSCC?

- There is not a right or wrong way to feel. It might be a shock and the initial treatment can seem quite frightening, especially if you have to lie flat for a while. Some people are more relieved that their pain and symptoms are being treated. You may have many different emotions and that is normal.

Is it normal to feel a range of emotions?

- Everyone is different. People will have their own way of coping with stress and this depends on a range of factors including your past experience, your usual response to stressful situations and the support that you are getting at the moment. It is normal to feel strong feelings in what is a very unusual situation.

What should I do about my feelings?

- Some people find it comforting to talk to someone close to them, such as friends or family. Research shows that getting support is a really important part of coping with stressful life events.

Quality of life

I do not want to burden my family and friends by talking about it, what should I do?

- There is always the option to talk to a professional - please contact us and we can advise you on counselling available to you. Macmillan Cancer Support offers telephone support, 7 days a week, 8am-8pm call them on 0808 808 0000. You might also find it helpful to talk to one of the cancer nurses you already know.

I would like to be able to talk to my partner about this, but I do not know how to start, what would you advise?

- Being honest with each other will help, but living with cancer can be stressful and many couples find their own ways of communication and coping. If you are finding this hard but would like to talk, couples counselling is available to help you both come to terms with what is happening and to encourage open and honest conversation between you.
- Macmillan is working with Relate in Buckinghamshire to offer free counselling sessions to those with cancer, their family or carers. Ask your MSCC team or Clinical Nurse Specialist to refer you.

What if I do not want to talk?

- Some people prefer to keep their feelings to themselves. There is no right or wrong way to cope, but help is there if you need it.

Other support available to you:

You might find it helpful to join the national charity the Spinal Injuries Association (SIA) – www.spinal.co.uk 01908 604191.

It is free and they provide good information about bladder and bowel management.

How can I help reduce healthcare associated infections?

Infection prevention & control is important to the well-being of our patients and for that reason we have infection prevention & control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. We ask that you, and anyone visiting you, use the hand sanitiser available at the entrance to every ward before coming in to and after leaving the ward. In some situations hands may need to be washed at the sink using soap and water rather than using the hand sanitiser as hand sanitisers are not suitable for use when dealing with patients who have symptoms of diarrhoea.

www.buckshealthcare.nhs.uk

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