



National Assembly for Wales
[Health and Social Care Committee](#)
[Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan](#)

Evidence from the Macmillan Metastatic Spinal Cord Compression Service Improvement Lead for the South Wales Cancer Network – CDP 05

 <p>Rhwydwaith Cancer De Cymru South Wales Cancer Network</p> 	
Briefing for:	National Assembly for Wales' Health and Social Care Committee
Purpose:	Response to the inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan.
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Introduction

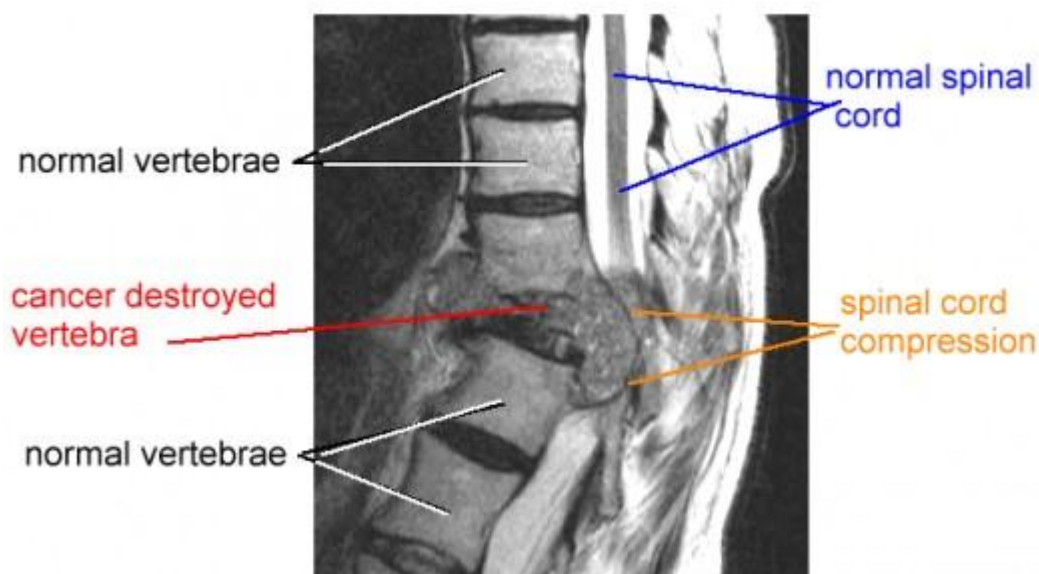
1. We welcome this inquiry into the progress made to date on the implementation of the Welsh Government's (WGs) Cancer Delivery Plan (CDP) by the National Assembly for Wales' Health and Social Care Committee.
2. We have not provided answers to all the questions posed by the inquiry but are looking at 'Whether Wales is on course to achieve the outcomes and performance measures as set out in the Cancer Delivery Plan, by 2016'. Within the 'Meeting People's Needs' section of the CDP there was a duty on Local Health Boards to '**Plan and deliver co-ordinated services for metastatic cancer patients and measure outcomes**', and our response specifically deals with this action and the needs of patients who are at risk of metastatic spinal cord compression (MSCC).
3. Our response is based on our experience working within the health profession and learning's from the Macmillan and South Wales Cancer Network Metastatic Spinal Cord Compression Project. We have significant experience of working with patients with MSCC. We both come from a physiotherapy background, with over seven years of Specialist Oncology and Palliative Care experience. We are currently seconded into a Macmillan Metastatic Spinal Cord Compression Service Improvement project which started in October 2013 and is funded for a two year period. The broad aim of this project is to develop a standardised strategy for the management of MSCC patients across South Wales and roll out an education programme for all health care professionals to raise awareness of MSCC.
4. We recommend that;

a. A dedicated MSCC co-ordinators is provided in each Cancer Centre in Wales, as per NICE guidelines. This will enable us to provide a streamlined, seamless service for patients with potential, or confirmed, MSCC.

- b. A strategic approach to cancer patient information is provided to ensure patients who have cancer that has spread, or is at risk of spreading, are given high quality information that explains what to do, and who to contact, if they develop symptoms of spinal metastases or MSCC, as per NICE guidelines.*
- c. A long-term strategy is produced in Wales to standardise the management and care of MSCC patients. Treatment for MSCC should be started as soon as possible after diagnosis with the aim of minimising permanent damage to the spinal cord, including paralysis.*
- d. The Welsh Government works with Local Health Boards to develop a standardised education package for all Health Care Professionals in Wales to use.*

About Metastatic Spinal Cord Compression

- 5. MSCC is a highly complex debilitating complication of cancer which **affects 5 - 14%ⁱ of cancer patients** (most commonly those with breast, prostate, and lung cancers).
- 6. People who have cancer, whether they have a known primary cancer diagnosis or not, are at risk of it spreading to other parts of their body including the liver, lungs or bones. When cancer spreads it is known as 'metastatic'.
- 7. Cancer that has spread to the spine is known as 'spinal metastases'. Spinal metastases can be painful and if not treated can lead to metastatic spinal cord compression. MSCC is when the spinal metastases press on the nerves in the spine that carry messages between the brain and the rest of the body. If it isn't treated quickly, MSCC can lead to serious disability, including permanent paralysis, and early death.
- 8. Signs and symptoms of MSCC include;
 - a. back pain, which is the most common presenting feature and may be associated with referred pain to the torso or limbs;
 - b. reduced muscle power;
 - c. sensory abnormalities;
 - d. bowel and bladder dysfunction.



9. MSCC is a complication of cancer and is deemed an oncological emergency due to the devastating effects it can have on people. Research has shown that 77% of patients diagnosed with MSCC had an established diagnosis of cancer whereas 23% presented with MSCC as the first presentation of malignancy.ⁱⁱ
10. Audits have demonstrated that there are significant delays from the time that patients first develop symptoms to recognising the possibility of MSCC. It's important that **people who have cancer that 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.** Treatment should be started as soon as possible after diagnosis with the aim of minimising permanent damage to the spinal cord. Treatment will also help to reduce pain by shrinking the tumour and relieving the pressure on the nerves. The damage to the spinal cord means that some people will have some paralysis at the time of diagnosis. This may be permanent in some people.
11. Studies have consistently demonstrated that if MSCC is diagnosed late a patient's ability to walk after treatment is directly associated with the ability to walk at time of MSCC diagnosis. Around 50% of patients with MSCC present to health care professionals unable 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.ⁱⁱⁱ It is therefore imperative to diagnose this condition early to prevent irreversible neurological damage that can affect a patient's mobility and function.
12. Allied health professionals, particularly physiotherapists working in primary, secondary or tertiary care, will often be treating patients 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 means that surgery can be considered, and steroid prescription and radiotherapy commenced.

13. People who have cancer that has spread, or is at risk of spreading, to their bones should be given **high quality information that explains what to do and who to contact if they develop symptoms of spinal metastases or metastatic spinal cord compression as per NICE guidelines**. This information, preferably in the form of an alert card, should also be given to people who have bone metastases so that they are aware of the symptoms and are able to seek support from primary or secondary care professionals so that it can be investigated and the symptoms managed. **Presently in Wales information is not provided consistently to cancer patients in Wales about the symptoms of MSCC and this is vital to support people to seek support.**
14. The Incidence of MSCC is likely to increase as the cancer survival rates continue to improve with advancing oncological treatments therefore **we recommend that a strategic approach to cancer patient information is provided to ensure patients across Wales can consistently access high quality information in a format which meets their needs.**

About Macmillan and South Wales Cancer Network Project

15. This Macmillan and South Wales Cancer Network Project is funded for two years. The aims and objectives of the project fulfil and set standards against Macmillan's 'Value Based Standards', Macmillan's long-term consequences of cancer and its treatment agenda and Macmillan's survivorship agenda. Macmillan is honoured to be at the forefront of supporting a project which will make a colossal change within MSCC services across South Wales. In addition, the Project will have a positive impact on the lives of people affected by cancer by implementing best practice and patient centred care. Macmillan acknowledges the demand and importance of the MSCC Service Improvement Project within South Wales.
16. The Project will be leading the way forward within primary and secondary care in aiding all patients located in South Wales to be able to access the best possible treatment for MSCC and therefore maintaining mobility due to timely access to support.
17. To date we have carried out initial scoping sessions and will be setting up treatment pathways, based on the 2008 National Institute for Health and Care Excellence guidance, and aim to introduce an educational programme for healthcare staff, including physiotherapists, and particularly aimed at GPs working in A&E.
18. We believe that the Project will have invaluable quality of life benefits for patients and NHS cost benefits through reducing length of stays plus preventing admissions, which is paramount.
19. The two broad aims of the project are:
 - a) **To develop a long-term strategy to standardise the management and care of MSCC patients and implement across South Wales (six Health Boards and Velindre NHS Trust, serving a population of 2.3 million).**
 - b) **To provide, and deliver a standardised education package for all Health Care Professionals to use.**
20. A gold standard pathway is required for the management of MSCC across the South Wales Cancer Network, which can then be rolled out across the whole of Wales. The

pathway should provide patients with a high level of standardised care, aiming to improve patient's quality of life by maintaining their function and achieving individualised goals.

21. In 2008, the MSCC NICE guidelines were published to guide Health Care Professionals in providing evidence based care and states that a patient with a history of cancer and recent altered neurology consistent with MSCC needs to be referred to the MSCC coordinator URGENTLY (within 24 hours). Following recent investigations within the South Wales Cancer Network, there is evidence to suggest that this recommendation is not consistently being adhered to. There are very good quality Local Health Board and Trust pathways available across the South Wales Cancer Network, but the services are inconsistent both within and between the East and West of the South Wales Cancer Network. Consequently, this has a significant impact on outcomes within the management and care of MSCC patients.
22. It has been predicted that referrals for common cancers will continue to rise over the forthcoming years. The Wales Cancer Intelligence and Surveillance Unit (WCISU) have predicted that cancer incidence of the prostate, large bowel and breast in Wales will rise by 41%, 28% and 25% respectively by 2015 compared to reported levels in 2003. Hence, this will cause an increase in demand on MSCC services as there will be a potential increase in the number of MSCC diagnosed.

Recommendations

23. As highlighted previously, we recommend that;

- a. ***A dedicated MSCC co-ordinators is provided in each Cancer Centre, as per NICE guidelines. This will enable us to provide a streamlined, seamless service for patients with potential, or confirmed, MSCC.***
- b. ***A strategic approach to cancer patient information is provided to ensure patients who have cancer that has spread, or is at risk of spreading, are given high quality information that explains what to do and who to contact if they develop symptoms of spinal metastases or MSCC, as per NICE guidelines.***
- c. ***A long-term strategy is produced in Wales to standardise the management and care of MSCC patients. Treatment for MSCC should be started as soon as possible after diagnosis with the aim of minimising permanent damage to the spinal cord, including paralysis.***
- d. ***That the Welsh Government works with Local Health Boards to develop a standardised education package for all Health Care Professionals in Wales to use.***

ⁱ NICE, 2008 Metastatic spinal cord compression: Diagnosis and management of adults at risk of and with metastatic spinal cord compression

ⁱⁱ Levack P, Graham J, Collie D et al. (2001) A prospective audit of the diagnosis, management and outcome of malignant spinal cord compression. Clinical Resource and Audit Group (CRAG) 97/08

ⁱⁱⁱ Helen Tyler, Specialist Oncology Physiotherapist and Therapies Service Manager, Velindre Cancer Centre
<https://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Newsandupdates/MacVoice/Spring%202013/Metastaticspinalcordcompression.aspx>