

Senedd Briefing:

A New Deal for Metastatic Breast Cancer in Wales?



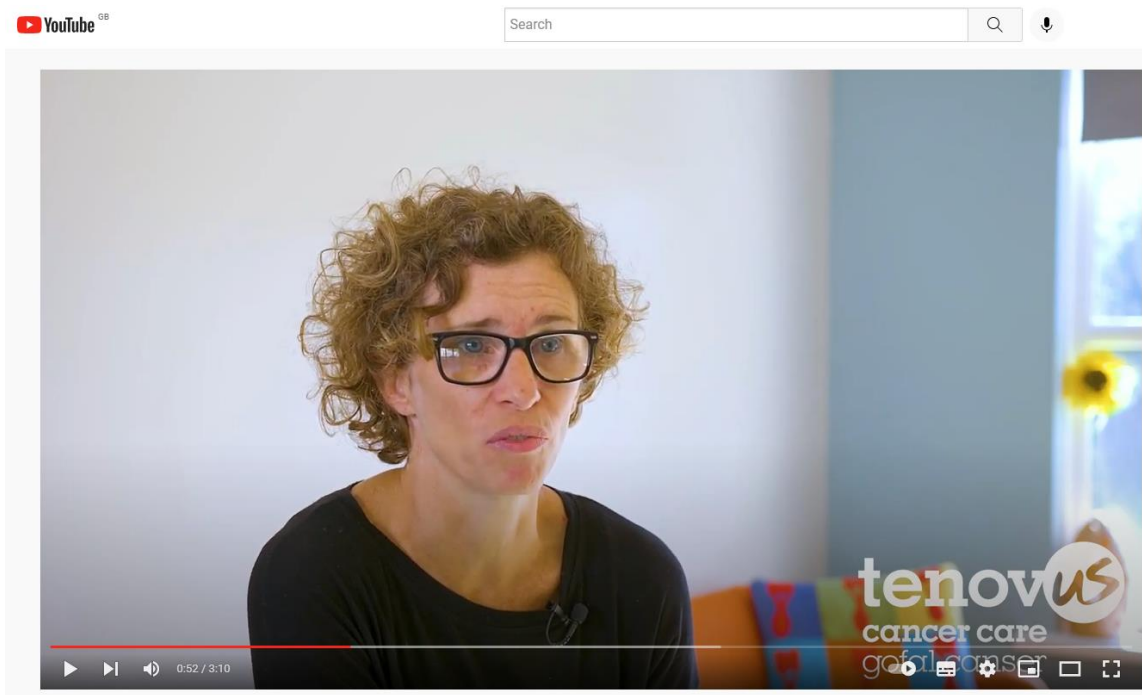
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Carolyn's Story

Carolyn Gammon was diagnosed with breast cancer while pregnant in 2015. After her daughter was born, a scan revealed her cancer had spread to her liver and lungs. In 2019 - prior to passing away from her cancer in September 2020 - [Carolyn shared her story with Tenovus Cancer Care.](#)

Please take time to listen to Carolyn's story.



Background

As a result of the petition 'P-06-1294 Don't leave metastatic breast cancer patients in Wales behind' receiving 14,106 signatures, Jack Sargeant MS has proposed the following NDM 8103 for debate on the 19th October 2022;

"To propose that the Senedd:

Notes the petition 'P-06-1294 Don't leave metastatic breast cancer patients in Wales behind' which received 14,106 signatures."

The petition reads:

Petition Number: P-06-1294

Petition title: Don't leave metastatic breast cancer patients in Wales behind

Text of petition: People living with metastatic breast cancer (MBC) in Wales are being badly let down by the system. Currently, Wales has just one dedicated secondary breast cancer clinical nurse specialist (CNS), a situation that leaves potentially hundreds of people without adequate support. We need to know how many people are living with MBC to improve services. And we want improve quality of life outcomes by raising awareness of MBC red flag symptoms.

We are calling for:

1. Every person with Metastatic breast cancer (MBC) in Wales to have access to a

dedicated secondary breast cancer clinical nurse specialist.

2. A collection of data of those living and being treated for MBC in Wales.

The NDM is due to be debated on Wednesday 19th October 2022.

Tenovus Cancer Care urges Members from across the political spectrum to contribute to the debate .

Breast Cancer in Wales

Breast cancer, which comes in several forms, will develop in different parts of the breast. About 1 in 8 women are diagnosed with breast cancer during their lifetime. There's a good chance of recovery if it's detected at an early stage¹.

It's vital that women check their breasts regularly for any changes and always have any changes examined by a GP, and breast cancer screening services are available to women between 50 and 70. Women with a higher-than-average risk of developing breast cancer may be offered screening and genetic testing.

In rare cases, men can also be diagnosed with breast cancer.

Metastatic, also secondary or advanced breast cancer happens when the cancer has spread to other parts of the body. Also known as Stage 4 breast cancer, the cancer is incurable, though it may be treatable to relieve symptoms, pain and discomfort.

Treatment for metastatic breast cancer aims to reduce the size of tumours; increase quality of life and prolong the life of the patient to spend time with their loved-ones.

The Key Worker/Clinical Nurse Specialist (CNS)

On diagnosis of cancer, patients should receive the details of a key-worker² – ordinarily a cancer clinical nurse specialist (CNS) who understands the clinical context the patient finds themselves in and is on hand to provide care, information and support. The Key Worker:

“...takes a key role in coordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice.”

Despite the Welsh Government guidance in 2014, the 2016 Wales Cancer Patient Experience Survey (WCPES) found that around one in five cancer patients did not know or have access to a key worker, many people in that figure would have metastatic breast cancer. At the time of the survey there was one metastatic breast cancer CNS in Wales, that unfortunately remains the case.

The findings of the WCPES show the difference access to a CNS makes and the further work needed to ensure all patients can access a CNS together with the importance of ensuring CNSs are adequately resourced to provide the wrap around care valued by patients.

Tenovus Cancer Care supports the petitioner's call for every person with metastatic breast cancer in Wales to have access to a dedicated secondary breast cancer clinical nurse specialist. A concerning number of patients across Wales do not receive the support and information they might otherwise receive if they had a primary cancer diagnosis.

¹ <https://www.nhs.uk/conditions/breast-cancer/>

² NHS Wales Circular, Dr Andrew Goodall (2014) Principles and Guidance - Key Workers for Cancer Patients
<https://gov.wales/sites/default/files/publications/2019-07/principles-and-guidance-key-workers-for-cancer-patients.pdf>

Tenovus Cancer Care also supports the Wales Cancer Alliance's call on the Welsh Government and NHS Wales to produce a plan for the cancer workforce³.

Relatively recent NHS Wales initiatives, such as the Single Cancer Pathway and Rapid Diagnostic Centres, are welcome but can only achieve so much without the right staff in place. There are concerning gaps in care and support, being experienced by metastatic cancer patients.

A joined-up cancer workforce plan, bringing together the different agencies, would determine how best to address gaps in the workforce. This may be through increasing training and recruitment, as well as using the existing workforce differently, where appropriate adopting a 'skills mix' approach.

Better Understanding Metastatic Breast Cancer

The number of patients affected by metastatic breast cancer in Wales is currently unknown. Breast Cancer Now estimates that there are 35,000 people living with metastatic breast cancer in the UK⁴, around 5% of the total number of people affected by breast cancer. Applying the 5% estimate to Wales, approximately 140 of the 2,800 people with a breast cancer diagnosis will go on to develop metastatic breast cancer.

However, these are best guesses. Until last year official data concerning metastatic breast cancer barely existed, and the insight that is usually gained for cancer service and patient experience purposes barely existed.

Tenovus Cancer Care supports the petitioner's call for the collection of data, meaningful data, concerning the diagnosis, treatment and support of metastatic breast cancer patients.

We welcome steps to rectify an historic inequality with regards to data. The first ever National Metastatic Breast Cancer Audit run by the Healthcare Quality Improvement Partnership (HQIP). The audit, to which NHS Wales will contribute, should provide - for the first time - accurate data around the number of people in England and Wales living with metastatic breast cancer. We look forward to publication of the findings.

Tenovus Cancer Care also endorses the Wales Cancer Alliance's 2020 call for a metastatic cancer plan to address the difficulties experienced by metastatic patients in diagnosis, treatment and living with their disease⁵.

A plan would urgently address the lack of data on metastatic cancers. The data on metastatic cancer patients is inadequate, meaning they can feel invisible and not receive the support they need. It can also mean greater difficulty re-entering the system for a diagnosis, accessing a key worker, or participating in clinical trials, which could mean additional options for treatment.

We welcome the commitment from the Wales Cancer Network to transforming the collection and use of cancer data through the new cancer informatics solution. It will enable clinicians to record secondary cancer diagnosis, helping to paint a clearer picture of secondary cancer across Wales and enabling better service, workforce and support planning.

Tenovus Cancer Care urges Members from across the political spectrum to contribute to the debate.

Thank you for your support.

³ Wales Cancer Alliance (2020) One Cancer Voice Cymru: A manifesto from the Wales Cancer Alliance <https://walescanceralliance.org/wp-content/uploads/2020/03/WCA-Manifesto-English-F1.pdf> (pg 3)

⁴ <https://breastcancer.org/about-us/media/facts-statistics>

⁵ <https://walescanceralliance.org/wp-content/uploads/2020/03/WCA-Manifesto-English-F1.pdf> (pg 6)