

P-06-1294 Don't leave metastatic breast cancer patients in Wales behind – An open letter from the patients of Metastatic Breast Cancer in Wales and those personally and closely supporting those with Metastatic Breast Cancer in Wales.

To the minister of health and social services

My name is Tassia Haines and I am a constituent of Aberavon. Unfortunately, I have been living with metastatic breast cancer (MBC) for over two years even though I am just thirty years old. I am receiving treatment from two health boards and have met people undergoing treatment from all over Wales, and regrettably I must inform you, Wales is failing when it comes to meeting the needs of MBC patients, according to us - The people dying from the disease and the close people supporting those with MBC.

The failures surrounding MBC stems from the insufficient implementation of previous cancer delivery plans and the more recent cancer quality statement which, not only preserves Wales as the only UK nation to not have a cancer strategy but neglects to exhibit accountability and therefore improvement when it comes to a jarring decline in best practice and patient care. Namely, combined efforts of the Welsh Government and the Welsh Breast Cancer Group have been ineffective in protecting patients from the inconsistent care received between health boards. Furthermore, there is still no data to show us how many people are living with MBC in Wales, despite the importance of this being raised and promises to rectify this in 2019. As a consequence, progression of care in this field has moved backwards, as we cannot measure the impact of interventions as people living with MBC remain an unrecognised/unknown group in terms of data.

Imagine having the knowledge that you are not only slowly dying but are also having elements of your identity and life robbed by this invisible, vastly misunderstood disease?

Can you comprehend what it is like to navigate your final months/years between disability, pain and death? and in my case be too sick to pursue a career and have a family, but is not sick enough to die, just yet? Now consider the feeling of impending dread as you realise the system you supported your whole life withheld the knowledge from you that could have potentially prevented this from happening and is also making you face your end alone?

Respectfully, you as Health Minister and our government have indirectly become the architects of this dystopian nightmare as the creators of this fractured framework. By not recognizing the importance of access to an MBC clinical nurse specialist (CNS) to every patient with MBC you have denied them a consistent partner who will be with them through their terrifying decline from a healthy, pain free life. An MBC CNS is more than a role; they are our familiar face between all the differing doctors, they are our voice when we are overwhelmed, they are our guides, our translators, the guardians of our dignity and most of all, they are our friends who will hold our hands through our end-of life care.

There must be some element of consistency and accountability centrally to allow health boards to do the best they can.

To help begin the urgent development of MBC care we propose three steps that must improve and be implemented:

1. Diagnosing MBC

1.a. Patients recovering from primary BC must be informed of the red flag symptoms of MBC.

1.b. They must all be made aware and have a direct line of communication to their BC teams when red flag symptoms do arise.

1.c. GPs must be made aware of the red flag symptoms of MBC especially when a patient has already had BC.

2. Data

2.a. We must have a central system to store data of those living with MBC, this enables us:

- To enable the needs of people with MBC to be identified and addressed
- To measure the effectiveness of interventions
- To inform financial and clinical investment where it is most needed

3. Workforce

3.a Pay health professionals appropriately for their over time. They need to feel more valued to be able to make best practice more sustainable.

3.b. Every person suffering from MBC MUST have access to a CNS whose workload is focused only on those suffering from MBC. Their role would ensure they:

- Act as the main point of consistent contact between differing health professionals for the patient (Surgeon, Radiographers, treatment nurses, pharmacists, oncologists, etc)
- Be there to analyse the holistic needs of each individual patient and refer accordingly (Therapies, counselling, benefits, etc)
- Work alongside Oncologists in designing personalised health plans and to deliver these to the patients and to act as the patient's representative within MDT meetings due to the specific individuals wishes and needs.

Please note this list is not exhaustive of an MBC CNS job specification.

As a unit of all those involved in those closely supporting and living with MBC. It is us - the patients and caregivers who wish to sign this letter in support for urgent change. We call upon you as Health Minister to help make the central changes we

need brought forward by this letter to bring back best practice within MBC and meet the needs of patient care.

Due to the lack of data of those living with MBC and their needs in Wales we feel this letter is an important step forward to represent our issues and desires for change.

Yours sincerely

The patients of Metastatic Breast Cancer in Wales and those personally and closely supporting those with Metastatic Breast Cancer in Wales.