

Dear Jack,

Thank you for meeting with us on Monday 17th ahead of the debates and the petition handover.

Unfortunately, we are very disappointed in Eluned Morgan's response to our petition. I call into question her commitment on improving cancer outcomes in Wales. If the Government fails to understand the fundamental issues between different types of cancers, then how can we entrust them to know about the specific issues each type of cancer presents?

We have no data on those living with Metastatic Breast Cancer (MBC), so how will the Welsh Government work with the NHS on accountability and planning without this information? Or does this mean people like us will continue to not be a part of these plans and will continue to go on unheard?

The [national optimised pathways](#) that are spoken of do not include MBC, on the contrary, there is a sad little arrow which points to the box we are in and as it nonchalantly reads 'See MBC pathway' that right there is where our support begins and ends. We do not have a pathway; we are forgotten and are continuing to die unsupported not even worthy of the pathway which is always thrown back at us in response. How can our Health Minister continue to let this happen? Like many others I can't have children, I am too sick to work and I can't afford my own funeral, we turn to the highest office in Wales to have evidence which has not even been adequately checked thrown back at us?

The Health Ministers expectations of professional standards are simply not being met as per the [NICE guidelines 1.4 "Supportive care"](#), 277 MBC patients and care givers in Wales have signed our [open letter](#) which agrees they are not receiving this care and need it. Furthermore, people presenting with MBC are not being supported by a multi professional team with specialist nursing as needed, 14106 people have signed our petition to do better. Please, I would strongly advise the health minister to do some research, or just simply meet with me and other patients to learn the horrendous realities we are having to contend with.

The contradictive elements in the Health Minister's response is feeding into the reality we are trying to highlight. The response states "It is not the Welsh Government's role to specify which conditions should benefit from dedicated specialist nursing support" and yet, on 8.3.22 [nurse appointments](#) were made to support those with endometriosis in every health board. Sure, any cancer *can* metastasize, but it is MBC which is the [leading cause of death in women age 35-64](#). Eluned Morgan has herself stated "Historically women's health services have not had equal treatment and women's voices have been ignored. I am determined that we raise the standards of all women's health services in Wales and this summer I will be publishing a Quality Statement setting out how that will be achieved." I am confused as to why the leading cause of death women 35-64 years old does not count as a woman's health issue. By her own words our voices are ignored.

Finally, I would like to draw attention to the fact the BCN audit will take place next year and will take a minimum of three years before we will begin to draw on any data. Where is the guarantee this will happen in 4 years' time? Data collection was mandated in 2012 and there were promises to rectify it in 2019. No, this data is needed now, WE are dying in real time and cannot keep waiting for someone to do something as simple as count us.

Please check the evidence and listen to the people of Wales.

Kind regards,

Tassia Haines

