

P- 06-1294 Don't leave metastatic breast cancer patients in Wales behind

Correspondence – Petitioner to Committee, 10.05.23

Dear Jack and committee members,

I regret to open this letter by expressing complete disappointment in the Health Ministers latest response. It has been exactly a year since the campaign and petition was launched, and the acknowledgement of the voices of over 14,000 people calling for change has yet to be addressed. Metastatic breast cancer (MBC) patients in Wales are still needlessly suffering in silence.

Between navigating the regime of a challenging palliative chemotherapy, hospital admissions, and dying, I often await the correspondence from the Senedd with a keen anticipation and interest.

Why?

Because I know what is like to die like this, and time is not on our side. Not one question from my last response has been adequately addressed.

Whilst I thank the Health Minister for repeating that work has started for a much-needed MBC pathway in Wales, I again, must insist on enquiring how the progress will be measured and who specifically will be accountable for ensuring this does get completed? Will patients also be involved in the pathways design? If not, how will we know it is meeting the needs of the patients? As per my last letter, we can see from the patient survey over two thirds of MBC patients in Wales were not offered a written care plan, (even less offered a holistic needs assessment) surely this illustrates the gulf between what patients need VS the reality? Additionally, if the health minister expects progress to be made on this, this year, then what are the government going to do to ensure progress will happen?

As per my last correspondence with the petitions committee, I would like to take the opportunity to ask once again, what were the outcomes of the other recommendations on the paper made during January's meeting to the cancer board? In the interest of absolute transparency, will this information be made available and when can we expect to see this? In the five months since this meeting has taken place, there has been no mention that the key points from the petition and open letter have been acknowledged during this board meeting.

If we are just replacing the functionality of CaNISC with a new system, how will it tackle our need for collection of data of those living with MBC. It was stated (in the last correspondence) the new system is not there to mine the data. So how will the patients see any benefit from gathering data when it is not clear how the new system will 'count' patients and extract this information to begin with? Without a clear picture on how long people are living with MBC assumptions and ill decisions will continue to attribute to the needless suffering.

As petitioner and a representative of the many thousands who are living and have died from MBC in Wales, I beg of you, to follow up from the points made during the debate. How can the members of the petitions committee ensure our questions are being acknowledged? Can we count on you to apply this pressure in the chamber at any opportunity? Is there anything more I can be doing under your guidance?

I apologise if I have lacked clarity or if anything has been 'lost in translation'. As time moves on, I am struggling with each correspondence as a result of treatment and condition. As the opportunity has

not presented itself within the last year, I would be very open to a meeting with the Health Minister to share the reality of this disease, clear up any confusion made on my behalf, and to discuss how we can move forward more effectively.

I sincerely hope the petitions committee will allow us to continue to move forward.

Yours sincerely, Tassia Haines