

Committee Secretary
Select Committee into Funding for Research into Cancers with Low Survival Rates
Department of the Senate
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Dear Committee Secretary,

Funding for Research into Cancers with Low Survival Rates

My husband, Idris was diagnosed with brain cancer in June 2016. He was 37 years old then and working full time. His symptoms increased from regular painful headaches, personality changes to extreme dizziness. He went to see a GP, who thankfully sent him for a CT scan. I am interested in this issue due to the personal circumstances of my family. There is no known cause or cure for brain cancer and learning the statistics for this type of cancer is pretty scary. There doesn't seem to be a lot of recent studies that relate to his particular type of tumor (Oligodendroglioma, grade III). All the statistics are for the total overall patients with brain cancer, but they vary greatly so it is hard to understand what it means for us personally.

My husband has had surgery, radiation and is still undergoing chemotherapy treatment. It may be some time before he is able to be strong enough to work again. We had to move interstate to be closer to family for additional support and for financial reasons, we simply could not afford to continue living in Sydney with one salary. We have a 2 year old child and I need to work full time to support our family.

Besides research into treatment or prevention, I think more funding is needed in areas such as patient care. Our experience of the health care system has varied greatly. I feel that the oncology department of the hospital that my husband is being treated in now is completely overworked. It makes the oncologist appear as uncaring. They have made some mistakes with his treatment, and lack communication to us about what they are doing. There seems to be very few oncologist that have specialization in brain tumors. I understand that is most likely due to the number of patients with this disease compared with others like breast, lung or bowel cancer. So even if we wanted to look for a specialist oncologist there doesn't appear to be any (not where we currently reside).

I have not seen any clinical trials available that my husband could take part in. I have not seen any for brain cancer, and besides doing my own research online I can't really find where to get this information.

I look forward to seeing what results come from this committee.

Yours faithfully,

Emma Bhatti