

Select Committee into funding research into cancers with low survival rates

Dear members of this committee,

I am a 51 year old self employed trade qualified house painter whom 5 years ago was diagnosed with an brainstem glioma via a CAT scan and MRI after experiencing some strange headaches. The current medical treatment is observation yearly via MRI, there is no cure or treatment, that has been the case over many decades, commonly a pediatric cancer it is rare in the adult population.

Some recent studies and trials have seen hope in dendritic cell immunotherapy, funding and a low number of patients seems to slow the pace of a positive outcome in finding a cure or life extending treatment. The current situation for parents whom are unlucky enough to have a child diagnosed with this disease is reason enough for a solution to be found in funding and finding a treatment ASAP as the brainstem gliomas have a 100% death rate in far shorter period of time in children than in adults.

I have continued to work paying taxes and collecting GST as my condition deteriorates with a spino -thalamic disturbance and affected gait. I will never collect an aged pension as I will be dead. The GST collected by long term terminal patients whom continue to work should be diverted to research into rare cancers, as for income taxes the same could be considered for exemption for the those of us who keep working instead of claiming a disability pension. The current definition for being a Terminal patient needs rectification for persons in my current medical status denies that definition, yet it is a 100% non survivable condition.

The current funding methods need more federal government involvement in assisting various fund raising bodies in medical research rather than military funding in the billions announced year on year. How about a billion on brain cancers, The collecting of DNA or brain banking or gene studies has never been mentioned by any of my doctors, WHY?. It seems nothing is really going on in Australia, the only clinical trial for this brain cancer after searching on the net for hours started in the Alfred hospital in Sydney in 2012 and was funded by the doctor doing the trial, it is a national disgrace that with so much revenue being wasted on crap like the f-35 fighter jets, football stadiums, recent federal ministers snouts caught in the trough, that our system of government is failing to see the needs of us suffering every day. The failure of this committee to create change in the way that is URGENTLY required will end with many young children dying and parents lives destroyed from the nightmare of losing a child. Adults with the disease must either keep working or suffer the consequences of losing the family home prior to dying as you are living longer than 12 months, with that making you unable to claim your life insurance and if you try to find a job outside of your trade the prospective employers medical is a hurdle you cannot escape.

Maybe a Federal Government fund could be created that allows people who are dying but will live longer than 12 months that pays 90% of the persons life insurance to them so family homes ect are not lost then the government becomes the 100% recipient of the insurance policy. When the person dies the government makes the 10% not paid for the running costs of this Federal department.

Yours sincerely,
Thomas Murkin