

Submission to:

Inquiry into services and treatment options for persons with cancer

by:

Elizabeth Haywood PhD.,

I am the principal carer for my husband (53) who has a Glioblastoma Multiforme (GBM) tumour in his right parietal lobe, diagnosed April 2004. He has undergone three craniotomies, radiotherapy, 6 rounds of temozolomide and one round (so far) of carboplatin. His prognosis, we have been told many times, is poor.

I am a member of the OZBrainTumour group – an internet mailing list of like minded sufferers and carers.

I have addressed each of the terms of reference – my submission is in *italics*.

Terms of Reference

On 10 February 2005 the Senate referred the following matters to the Senate Community Affairs References Committee for inquiry and report by 23 June 2005 .

(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

(i) the efficacy of a multi-disciplinary approach to cancer treatment,

The “standard” treatment for GBM includes surgery, radiotherapy, and chemotherapy. In addition, patients often suffer from epileptic fits and have other neurological problems, such as physical disabilities. Our experience demonstrates that all these issues require the patient to consult with experts in each of these fields i.e. neurosurgery, radiation oncology, medical oncology, neurology/epileptology, physiotherapy and occupational therapy.

Our experience also demonstrated that there seems to be a lack of knowledge (or recognition) by the surgeons (for example) that consultation with experts in the other fields is actually needed.

(ii) the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers,

The very fact that GBM patients need to consult all these experts and that surgeons (usually the first line of medical treatment and often via

an emergency trip) don't have time/knowledge/inclination to refer patients to the other experts, a case manager is needed.

In our case, that turned out to be me. It would have been useful if I had even been made aware that I would have to take on this role. Even better if someone at the hospital had been able to inform me of the very fact that these experts existed. Our GP was less than useful – sympathetic, but...

I realised – eventually - that I needed to be informed about the disease, treatments, prognosis etc. (by means other than medical doctors) in order to begin to work out what help we actually needed. Then I was better able to work out who to consult, and then obtain what we thought was best treatment.

The problem with GBM is you don't have time to muck about working out who to consult. By the time I found out about some treatment that might have helped, and we consulted with (yet another) oncologist, my husband was already deteriorating, and ended up in hospital having the second operation.

(iii) differing models and best practice for addressing psycho/social factors in patient care,

I'm not sure of the current model... We were referred to a social worker at the big city hospital, but that was help with getting benefits, there was no offer of counselling – we got most help in that regard from one of the graduate (ie. first year) nurses.

We needed counselling on day of diagnosis – and again the day after maybe. It really was appalling, to be told, by a junior doctor that you had one of the most aggressive diseases and that your chances of surviving beyond 18 months was very slim. This was told, at bedside in a public ward. We could have been at least told in a little room somewhere, or something – instead he spent about 5 minutes with us, and left. I am still horrified that this is the practice.

We had very little contact with the doctors at that time and referrals were made to radiation oncologist only. There was no indication that other treatments might be available (but not on PBS...). Mind you, the radiation was private – and we don't know why this was so (we had to pay the "gap") – somehow, the patient doesn't belong in the loop of decisions made about his or her welfare. Is this true of all public patients? Or is it that talking to someone who has a death sentence hanging over them is hard, and therefore avoided by many medical staff?

However, the support we now get from (Bendigo region) palliative care, and carer support, is excellent – but you have to be referred to this,

and you have to be considered in need of it – another bitter pill to swallow.

- (iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians.

Being near a regional centre is great for general health issues, but not for something as big as a Brain Tumour. Treatment – even MRI scans necessitate a trip to a major city centre. There is no doubt that regional patients are disadvantaged in that regard. However, as we have now found an oncologist who is willing to consult with a specialist in the city centre, we are feeling more confident in our treatment options. It meant a trip to see the consultant in the city, but that was well worth the money (private consultation....) and our local oncologist takes advice from the specialist.

Even better would be a brain tumour centre where world's best practice is offered and rural and regional doctors are able to tap into the centre's expertise. Where patients may have to travel to the centre for surgery and initial consultations, but post op care and other treatments can be provided locally.

- (v) current barriers to the implementation of best practice in the above fields;

Ignoring the obvious funding issues, I think the biggest barrier is the attitude of medical doctors. I believe their education/inclination is scientific in nature and I respect that many of them have worked hard and are very knowledgeable.

However, many (not all) of the doctor's we have consulted do not consider that anyone else has the ability (or the right?) to interpret results from medical trials, or to suggest treatment options. Discussions with various doctors has led to incredible frustration because they are only able to suggest standard, PBS supported, evidence-based treatments. This is OK for someone who has years of life ahead of them, but not for someone who they say has only months. It would have been nice if the first oncologist we consulted (prior to radiotherapy) had said – "well, there is this promising regime, but it isn't supported by PBS and it would cost you \$X". But no, not even a mention of the name of the chemotherapy (temozolomide) that might be useful in GBM.

To me, this amounts to negligence.

(b) How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:

- (i) the extent to which less conventional and complementary treatments are researched, or are supported by research,

I'm not sure how much it costs to mount decent trials, so that doctor's accept the results of them, and I fully accept that anecdotal evidence is just not enough for most people (including me to be honest).

I really wish that funding were made available for some trials involving complementary therapies. I'm pretty sure that most GBM patients would put their hand up to trialling complementary therapies – as opposed to “alternatives”.

There seems to be very little happening in this country – back to the idea of brain tumour centres – that might spawn such research if it were a major centre of cooperating experts... there would be an easier access to patients, easier central recording of results etc. There's nothing like being able to walk down the corridor to consult with someone... I do know this one... I know research... if you have to arrange to meet, if it has to be done by phone (or email), its not as good as a stroll or a chat over coffee!

(ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies,

I think, most of all, patient's need to be informed of their choices. I am now much better informed, and haven't pursued many of the alternative possibilities (mainly because of medical doctor argument, but at least we have had the discussion!).

I would have liked to have easier access to information, earlier.

I am well educated – an academic even – one who is able to research and is able to communicate. I found it hard. How much harder is it for someone who does not have these tools to hand? Impossible for many – they have to rely on the advice given by doctors – and that advice, is often lacking.

(iii) the legitimate role of government in the field of less conventional cancer treatment.

I see no difference in conventional and less conventional. They are all potential treatments for an awful disease. The difference is that conventional treatments have been proven by some trial... less conventional ones haven't yet had the support for a decent trail. The trial might “prove” they are useless – good, lets get it off the list of “potentials”....

Government has a major role to play in funding this research.