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Select Committee into Funding for Research into Cancers with Low Survival Rates
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Senate Select Inquiry into Brain Tumour Research Funding

Explain who you are and why you are interested in this issue}

My name is Dianne Pooley known as Di Pooley. I am 69. I am a retired professional. Aged Care, Dementia Specific Worker, in Management roles, Staff Educator, Continuous Improvement & Infection control in both residential and Community settings. I Was also involved in auditing facilities in preparation for Accreditation and involved for many years in innovative community program developments from submissions to Federal Government funding body, acceptance, staff recruitment, training, service implementation, Federal Government evaluation and roll out.

The following points are major issues for many meningioma survivors I am connected to and I am very keen to have these issues addressed for all who will face brain tumour diagnosis and treatment Benign or Malignant currently or in the future.

{Do you have a story or stories that help explain your point? Write them here}

Think about:

= How were you diagnosed?

My Goodness where do I begin? Around 2006 at the age of 59 I experienced an onset of Visual disturbance, classically described as Migraine. Flashing kaleidoscope swirling silver in an arc. Originally suspected a detached retina. Not so. No headache as such. These episodes occurred around 4 or 5 times a year again with no headache to speak of, extreme tiredness and nausea with elevated Blood Pressure. I was also at that time diagnosed with severe depression and commenced on 60mg of Avanza at night as I was having difficulty sleeping. I was working full time plus caring for my daughter and her young family before and after work

2012 I retired to help my sister care for my Mother who was 91 and had become palliative.

2014 & 2015 I had two intense episodes of unbearable head and facial pain which GP assumed was sinus infection and no further investigations were ordered. Visual migraines continued

2014 my health started to decline rapidly with severe balance issues, struggling to get in and out of bed or roll over in bed. Struggled to get up off the lounge, massive head spins, muscle weakness eg unable to use a can opener or take the top of a milk bottle. My mobility was poor, shuffling of feet and spatial judgement declined, speech became slurred and facial masking. My personal care was declining and I was no longer managing to maintain my home as usual.. GP wrote off balance symptoms as ear problems. Friends and family expressed concerns and insisted I return to GP, he then felt I may be developing Parkinson's as the symptoms were very similar and under my insistence he made a referral to a local Neurologist. No urgency expressed and I had to wait 3 months to see her.

Finally 25.9.2015 I saw neuro who ordered an MRI which was done 5 days later. Following the MRI I was given CD to take back to Dr and I returned home. My eldest son arrived a short time later as he had received a call from the radiologist requesting he locate me and take me immediately to Gosford Hospital where neurologists would be waiting to see me ASAP. On arrival neuro waiting as stated and I was informed I had a large mass on my brain that required immediate attention, I was admitted 30.9.2015 and commenced on dexamethasone and Levetiracetam and transfer by ambulance to Royal North Shore was hospital arranged. While waiting for the ambulance I had a fall. Transfer took place around midnight and I was admitted at RNS early am 1.10.2015 Drs expressed concern re immediate action required. I was informed a Neuro surgeon Mr Yanni Sergides was operating the following morning 2.10.2015 at North Shore Private and he could perform my surgery first thing. I was transferred to NSP late 1.10.2015 and underwent a 7 ½ hour surgical craniotomy to remove a large 8cm x6cmx4cm benign meningioma.

= **How did you feel?** Surprisingly at the time I felt quite calm. Guess the reason being My emotions had shut down &

• **The frontal lobes are responsible for emotions, problem solving, judgment and motor function.**

= **How did you cope?**

I just went with the flow. I remained in hospital for 2 weeks and was then transferred to a neuro rehab hospital unit closer to home for an expected 6 weeks as my balance was extremely poor. Pushing myself I managed to be discharged after 2 weeks with twice weekly outpatient visits and a daily exercise program to continue at home. I was depending on a 4 wheel rollator frame to get around, as balance was still a major issue. I was unable to drive and due to lack of family support I commenced walking to the shops with the aid of a rollator frame. That involved a 5km round trip and at times I used a taxi or caught a bus. I engaged a private cleaner to help until I was capable again. Many other survivors have lost their employment at a young age and their normal way of life had altered drastically.

= **How has it impacted on your life and the lives of your family?**

The impact on my life has been immense as my emotions are all over the place due to side effects of medications to prevent seizures. I have consulted with a psychiatrist who agrees the side effects are from the meds which after discussions with NS cannot be changed. My immediate family i.e. Sons and ex husband betrayed me while I was in hospital recovering, going through my personal things eg bank statements then eldest son confronted me & telling me I must curtail my spending habits. He was also critical of the state of my home, which he tidied up prior to my coming home. This came 2 days after I was discharged, my reaction was intense and I have not seen or heard from him since, which was 16 months ago and he lives 10 to 15 minutes away. That demonstrates a major previously unseen character flaw in him. Which has crushed me completely.

= How has it impacted on you socially/financially/emotionally?

Socially my life is great as I have a wonderful network of valued friends who have been amazing in their love and support to me.

Financially I was fortunate to have no out of pocket expenses. At the time, I had no choice in hospital or surgeon as it was an emergency situation but fell into the hands of a Brilliant Surgeon and follow up rehab specialist. I am privately insured and all was covered fortunately as all Dr involved and both private hospitals had agreements with my fund HCF to accept their rebate as full cover.

Emotionally

As stated my emotions are all over the place due to meds and family betrayal, which has continued with other things happening to intentionally undermine my wellbeing. I do at times, when I allow myself to think I get overwhelmed by my experience. I control my emotions as best I can using constant activity, gardening, walking, renovating and playing music. Outcome of that is I am constantly losing weight Overall 10 klg with my height 5'6 now weighing 57kg I need to sort that out.

I have recovered well , with excellent care and follow up. Although I did have to find a new GP as follow up with practice I had attended for over 45 years was bordering on negligent My recovery has been better than anyone expected. I am and always have been a driven person and have pushed myself to recover.

What have been the difficulties or challenges? Do you have suggestions for how can they be addressed?

As my large tumour was benign the following points are not major issue's for me at this time. I did locate a local Meningioma support group which has been amazing and my reasons for wanting to participate in the Inquiry are looking at what many Meningioma survivors are experiencing with multiple recurrence, lack of medical support and follow through. As well as the many varied outcomes and deficits for all survivors.

Although I reassured there was little risk of recurrence around 30%, because of contacts gained I now hold grave fears of this happening. Currently I am on annual MRI review to monitor for recurrence. I have had two hospital admissions for intense headaches described as migraines and one 5 day stay for a severe vertigo episode where I was unable to stand up. This was followed up with an assessment and review with a vertigo specialist and has improved but I still have days where it is an issue. Usually a warning sign that I need to rest up a bit.

Statistics show there is a high rate of these tumor's developing and little or no known current research into why and the risk factors

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Think about:

- = Where to find information/support
- = How to access clinical trials
- = How to understand treatment options
- = Living long distances from medical treatment
- = Balancing quality of life with treatment decisions

Personal details

Dianne Rae Pooley