

**Submission
No 420**

**INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO
HEALTH AND HOSPITAL SERVICES IN RURAL,
REGIONAL AND REMOTE NEW SOUTH WALES**

Name: Ms Carla Bower

Date Received: 12 January 2021

My name is Carla Bower & I am a 48 yr old women from Bellingen NSW.

I was diagnosed with terminal stage 4 Ovarian Cancer in July 2017 at just 44 yes of age.

At the time I was was told to go home & prepare..Ide be lucky to make it 3 months.

...Im not even going to write about how as a known BRCA1 carrier all my symptoms were missed..or how when I was referred to the only gynaecological specialist in Coffs Harbour ..he recommended doing nothing ...just watching & waiting.

I'm writing this submission today because I'm exhausted...because there is just no access or support to obtain services for regional women with ovarian cancer. Im writing to make some noise because we die & we die quickly.

We don't have Ovary nurses or helplines..we can barely access basic information & specialist Ovarian cancer Doctors are few & far between.

The 5 year survival rate for all Ovarian cancers is less than 45% ...& for Stage 4 Ovarian cancer it is even less.

As mentioned I was diagnosed in 2017.

After diagnosis I travelled from Bellingen to Newcastle for extensive debulking surgery and follow up with specialist Cancer Doctors.

After surgery I was referred to a specialist Oncologist in Sydney to oversea six months of chemotherapy ...My Oncologist immediately placed me on a three weekly infusion regime at the Royal Prince Alfred hospital in Sydney & as such found myself travelling from Bellingen to Sydney every fortnight for treatment. I was not able to claim any assistance for travel at this time thru the IPAS because technically I was entitled to receive my chemotherapy infusions locally thru the Coffs Harbour Hospitals cancer centre but in order to do that would be required to go on a waiting list & my Oncologist felt that the Chemotherapy was urgent. I also applied for disability support at this time but delays in processing meant that I was without any income support for over 5 months until my disability support was granted. During this time my friends had to initiate a go fund me campaign so I could afford to eat, buy medication & pay rent.

I also had to sell most of my possessions to cover my fuel costs.

After six months of travelling for treatments I had exhausted all chemotherapy options & was placed on Avastin a maintenance drug that is also administered intravenously.

Fortunately Coffs Harbour were able to take me for the next 12 months of treatments so travel was reduced to just 45mins each way ...much better than the 7hr drive from Bellingen to Sydney each fortnight. After those 12 months all medical options I had available had been exhausted. There were no other treatment options.

Then in 2019 I was offered an opportunity to join a trial for Ovarian Cancer. A lifeline. A glimmer of hope. I eagerly joined the trial & for the past year have been attending the Prince Of Wales Hospital in Randwick to receive treatment & medication.

But yet again I am unable to claim any assistance for travel..trials are not deemed necessary medical procedures or appointments and as such not covered by the IPAS.

So Im still ctrying to cover everything financially on a disability support pension.

I cannot begin to explain the added stress that travel & lack of financial support adds to a terminal cancer diagnosis on top of the inconvenience that constant travel for treatment has caused to my daughters schooling.

Ultimately I am left with no choice but to relocate in my dying days from my regional home town & community to better access health services & financial support.

I dont want to spend my final days doing the maths to see how long I can afford yo go on & I don't want my daughters to have to fight or save up or go without to meet their basic medical needs. I want funding fairness for Ovarian Cancer & for regional patients.

We deserve hope & we deserve not to be abandoned in our final days.

Thankyou.

Carla Bower