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Cancer Patients' Assistance Society of NSW  
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Dear Committee,

## **SUBMISSION FOR NEW INQUIRY INTO HEALTH OUTCOMES AND SERVICES IN RURAL, REGIONAL AND REMOTE NSW**

Can Assist is the largest cancer support network in rural, regional and remote NSW; active in 56 branches with near 3,000 members. Our branches are operated by local volunteers who live and work in these areas and therefore have a detailed understanding of local needs. In the 2019 fiscal year we delivered some \$2.14 million in financial assistance (representing an increase of 40% over the prior 5 years) across more than 9,000 requests throughout country NSW.

Improving equitable access to cancer services for country NSW residents has been our mission for over 65 years. Our growth comes from community grass roots with each branch being initiated, funded and operated by locals. Our oldest branch (Forbes) opened in 1956 and our youngest branch (Merriwa) opened in June this year.

We consider ourselves a key stakeholder in this inquiry. We receive some 90% of our distress referrals through health workers of the Local Health Districts. We are highly regarded and well known throughout country NSW. We congratulate the government for conducting this inquiry and appreciate the opportunity to make a submission.

### **BRANCH MAP**



Each Can Assist branch town experiences unique and varied barriers in access to cancer treatment services. “Distance” from metropolitan cities matters when it comes to fair and equitable access.

### **Radiotherapy**

Lack of radiotherapy services across NSW is a key problem. It was this same problem that motivated the original formation of our charity in 1955 when all four radiotherapy units operating in NSW were located within 4 kilometres of each other in Sydney. Whilst circumstances have certainly improved since those early days, more sites need to be built. The length of time to administer radiotherapy (often 5-6 weeks) plus the fact that it is delivered as an outpatient makes it uniquely expensive for residents that do not live close to services.

As a group, we spent 45% of our assistance measures on travel and accommodation costs in the Fiscal 2019 year, but each branch tells a different story. Branches like Moree, Nyngan, Bega for example spend more than 70% of their client assistance dollars on travel and accommodation. Patients from these towns could be travelling anywhere from 450 to 600 kms return to access a regional radiotherapy service (in Tamworth, Orange or Nowra). Other branches like Armidale and Tumut that are much closer to radiotherapy services (around 220km return to Tamworth and Wagga Wagga respectively) still spend between 60-70% of their assistance dollars on travel and accommodation. Driving is the only real travelling option; for those that make the return journey daily; petrol costs, parking costs and time off work for carers/drivers all add up. Community transport options are varied, but many remain expensive when considering the daily trips for 5-6 weeks that are required for radiotherapy treatment.

Capacity constraints at the existing public radiotherapy sites (most notably Tamworth where there is only one machine and longer wait times) and the lack of specialised radiotherapy (like brachytherapy and more) requires many patients to travel to metropolitan areas or forces them into the private system where **gap payments** are significant. We are currently helping a pensioner from Finley who, after receiving her private health and Medicare rebate post radiotherapy treatment in Shepparton was presented with a near \$14,000 bill. Referring doctors often ask simple questions like – “do you have health insurance?” and make no further cost enquiries. In times of crises, patients simply go where their doctors tell them to.

Diagnostic tests, **CT scans and PET scans** are in short supply across rural and regional NSW. Patients are often required to undergo a PET scan 3 or more times over their cancer journey – most often this will mean a trip to the nearest metropolitan city. If you live in Dubbo – this is probably a near 800 km return trip to Sydney.

### **IPTAAS**

Operating as a not for profit, our accommodation facility in Wagga Wagga (Lilier Lodge, JV with NSW Cancer Council) charges very low rates and whilst IPTAAS is a great assistance out of pockets remain. IPTAAS gives no consideration to treatment location; accommodation in

Sydney or Canberra for example can be 3 or 4 times more expensive than Wagga. Lillier Lodge receives some 70% of its guests from Griffith, Young, West Wyalong, Hillston, Leeton and Narrandera. If it were not for our facility here our assistance numbers would reflect much high travel and accommodation costs in these Can Assist branch locations.

The 100km one way cut off is arbitrary. Cancer patients in Gunnedah fall a few kms short to access the subsidy. If they are under 65yrs of age, they have no access to other government help. Frankly, was it not for our work, many people would either delay treatment or skip it all together. We are frequently made aware of this reality.

Can Assist is a vital service.

### **Surgery**

Even for those residents of towns with major cancer centres, in many cases, travel remains necessary; for melanomas and any cancers above the neck, treatment in Sydney is required. For those cancers that can be operated on closer to home entry as a public patient is not assured. In Wagga for example, many patients are forced into the private system – if your cancer gives rise to Lymphatic problems for example, there is only one doctor and she is in the private system. Most patients who are referred to the RCCC from outside the public hospital system are admitted as private patients. There is very limited bulk billing at RCCC and it is not made easily available. Any Medicare rebate received must first be paid upfront by the patient and this can create cash flow problems. Our Wagga Can Assist branch spends some 75% of its assistance on medical out of pocket expenses.

Whilst **chemotherapy medications** continue to be listed on the PBS, we regularly assist patients with ongoing monthly out of pockets on these drugs.

### **Health Workers**

There are varying degrees of shortages across the state. Be it long periods of time before critical social worker roles are filled; fly in fly out doctors, part time nurses, oncologists and palliative care workers. Problems vary across the State; in Moree, it is not unusual to wait 5 weeks to see a GP, whereas west to Nyngan with a population less than 2,000, a day or two wait is not uncommon. We have very few oncologists, and limited palliative care workers.

End of Life services are limited across country NSW, and end of life drugs once outside of the public hospital system are very expensive (between \$400 and \$1,500 a month). From the larger centres like the Southern Highlands where a man dying at home of pancreatic cancer had no friends or family to help, our Can Assist branch there teamed up with another local charity to fund a night nurse for the 6 remaining days of his life. It has been left up to local community charities to fund hospice beds. Similarly, in Orange, community groups have come together to fund a palliative service in a local nursing home – set to expire in a matter of months, will Orange public hospital then step up?

In Moree, the solo palliative care nurse is run off her feet – providing after hours phone support and often working out of hours ...and there are similar stories in small towns across

the state; many of which share a palliative nurse from another town. It is no wonder it is so hard to get health workers into these remote towns.

The stories are heartbreaking be it the Mother of 3 children under 5 years of age from Lithgow whose treatments have meant weeks away from her family, culminating in her husband having to leave his job to care for their children, or the 7 year old brain cancer patient from Taree whose parents drove her back and forth daily to Newcastle for radiotherapy. These financial stressors would not be incurred by a family from Sydney.

The extra costs are crippling. Marlene from Merriwa made 10 separate trips back and forth to Newcastle; oncologists, CT scans, MRIs, PET scans (370km return) all before she even had surgery. 5 weeks of radiotherapy in Tamworth (300km return) plus accommodation, more PET scans in Newcastle and back to Tamworth every 1 to 3 months for check-ups. "It's thousands of dollars" and Can Assist only helps reduce these costs.

This brief submission is not designed to represent a comprehensive overview of the issues, but rather, a snap shot of our on the ground insights. More radiotherapy bunkers, more PET scans, more public facilities and more staff are needed across the state. Should the commission be seeking a more detailed analysis in specific areas we invite you to make direct contact with us. Disparity of access to healthcare between country and metropolitan NSW has a long history. The committee understand the injustice of this predicament and we thank you for the opportunity to share the insights of Can Assist. We look forward to a fairer health system for all Australians that gives no consideration to post code.

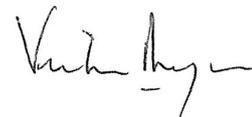
Yours sincerely,



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