**Submission No 32**

# THE IMPLEMENTATION OF PORTFOLIO COMMITTEE NO. 2 RECOMMENDATIONS RELATING TO THE DELIVERY OF SPECIFIC HEALTH SERVICES AND SPECIALIST CARE IN REMOTE, RURAL AND REGIONAL NSW

**Organisation:** Can Assist (Cancer Assistance Network)

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**Dear Committee,**

**SUBMISSION - INQUIRY INTO THE IMPLEMENTATION OF PORTFOLIO COMMITTEE NO. 2 RECOMMENDATIONS RELATING TO THE DELIVERY OF SEPCIFIC HEALTH SERVICES AND SPECIALIST CARE IN REMOTE, RURAL AND REGIONAL NSW.**

Can Assist operates with 3,000 plus volunteer members from 56 towns across regional, rural, and remote NSW. We aim to lessen the impact of distance to treatment and care through delivering financial assistance on a bespoke basis to our clients. In any given year we would typically answer over 10,000 requests and deliver between $2.0 and $3.0 million to cancer patients across country NSW.

As per the current terms of reference, we seek to share our views regarding the following areas of this Inquiry: community transport (recommendation 3), the current state of palliative care (recommendation 23), out-of-pocket medical costs for cancer patients accessing private/public services (recommendation 21) and engagement with local charities and understanding service gaps (recommendation 5).

**Recommendation 3 – Community Transport and service gaps**

The additional costs associated with private travel to treatment for isolated patients was swiftly and appropriately addressed post the 2021 Inquiry with a much-needed increase in IPTAAS rebates. In addition, and of equal importance was the establishment of a community forum aimed at the ongoing improvement and monitoring of the scheme. However, for those patients that are too sick to drive themselves and without a friend or relative to escort them, no such reform has been forthcoming. Road hazards like general disrepair, limited lighting, and kangaroos, combined with limited public transport and taxi alternatives makes an accessible and affordable community transport (CT) system vital for good health outcomes for residents of rural, regional, and remote NSW.

1. Cost of Community Transport

Government funding of this sector is inadequate and is delivered via a fundamentally flawed and inequitable allocation process. CT passengers are ineligible for IPTAAS rebates.

Ticket costs vary enormously across the state from as low as 17cents per km (e.g. Forbes to Orange) up to 200 cents per km (e.g. Tamworth to Newcastle). Some providers invoice for additional charges like driver meal allowance and brokerage fees and others do not. Most providers double the rate for the addition of an escort – others charge a deeply discounted fee.

Pricing is simply unaffordable for many and Can Assist is increasingly being called upon to fund ticket costs. We recently paid $455 for one return trip for a Commonwealth home support package (CHSP) recipient travelling from Moree to Toowoomba - (65cents per km). We regularly fund CT costs for access to radiotherapy; from Armidale to Tamworth for example, a CHSP passenger is charged $1250 over the course of a 5-week treatment profile. Should a passenger be receiving either a home care package (HCP) or the NDIS, charges rocket; to $2.00 per km or $1200 for one return trip from Tamworth to Newcastle for example (think PET scan) or $1.00 per km or $200 for one return trip from Cootamundra to Wagga Wagga (think daily radiotherapy for 5 weeks – a total cost of $5,000).

Patients using CT for medical appointments are ineligible to claim IPTAAS since it is considered "double dipping" into an existing government funded service. Government funding of the CT sector, however, is determined on a fixed per trip basis; around $37 per trip, regardless of kilometres travelled. In opposition to the philosophy of IPTAAS, passengers travelling for non-emergency treatment via CT are therefore effectively subsidized less per kilometre the longer they need to travel and charged the same rate as a passenger travelling for a shopping trip.

Over the course of a typical 12-month treatment profile, a rural cancer patient living just 100km away from the Tamworth Cancer Centre (the shortest distance for IPTAAS eligibility) would typically clock up a private travel IPTAAS rebate some 2.5 times the size of the equivalent implicit CT subsidy ($3862 versus $1517)[1].The disparity between the two subsidies grows exponentially with the geographic isolation of the patient since, unlike IPTAAS, the CT subsidy remains constant. The implicit government subsidy for CT is always lower than the equivalent IPTAAS subsidy for isolated patients (defined as those living at least 100km away from treatment). [2]

Government subsidies for CT are a complex web of Federal (via Aged Care – CHSP) and state (via Community Transport Program - CTP, and a NSW Health NGO grant program) funding. Overall, government funding of the sector is administered by Transport for NSW.

For the under 67's there are little or no government subsidies to be accessed. Whilst NSW Health grants (NGO grant program) are supposed to be accessible for this cohort, they are in fact legacy grants where applications have long been closed. Major regional CT operators like Oxley in Tamworth simply don't receive them. Moreover, we are aware that the CTP state-based funding (also for this cohort) is at capacity for some CT operators.

2. Accessibility of Community Transport

The problems don't stop there. In some cases, there have simply been no seats available for patients seeking lifesaving non-emergency medical treatment. Faced with no other options – one of our Can Assist volunteers from Cootamundra branch recently drove a 50-year-old community member who had no local family to assist her trip to Wagga Wagga for cancer treatment. He waited 5 hours for her to complete her treatment and then drove her home. On other occasions, she has only been able to access one leg of the trip (the return) and only on the day after treatment. In this case our volunteer drove her to treatment and arranged her overnight accommodation at our facility in Wagga Wagga (Lilier Lodge), so that she could

[1] Assume patient lives 100km outside of Tamworth who makes 37 trips to Tamworth and 4 trips to Newcastle.

[2] 200km is the minimum (return trip) distance a patient must travel to meet IPTAAS eligibility. At 40c per km this implies a minimum IPTAAS rebate of $80 (compared to a $37 CT subsidy).

return the following day via CT. These patients are the most vulnerable of patients – without nearby family to help. What happens to those patients in towns where Can Assist does not have a branch?

Accessibility to transport has been made all the worse with the new rollout of the Cancer Council of NSW travel to treatment offering – greater enforcement of their strict eligibility criteria and reduced services. Indeed, the Tablelands Community transport operator in Uralla has been forced to double their weekly trips to Tamworth since these changes.

Where reliable and affordable CT is not available – patients who would otherwise travel back and forth for treatment are forced to accommodate away from home. For a daily treatment like radiotherapy (often as short as only 10 or 15 minutes), this can mean up to 6 weeks away from home and brings with it a whole other raft of costs (additional lost income and lack of family support). In towns like Tamworth where there are only 9 NFP rooms available near the hospital, our clients are increasingly accommodating in the more expensive commercial sector where IPTAAS bulk billing is not available. If CT was more accessible more of our clients from Armidale for example would stay at home over the course of a radiotherapy; reducing costs for both Can Assist and the NSW Government[3] .

Moreover, given the general lack of alternative transport options, access to CT for shorter treatment distances must also be given serious consideration. Whilst residents of Forbes are only some 30km away from chemotherapy treatment at Parkes – there is simply no direct CT route to get them there.

Our CT operators work hard for their communities. Most if not all, draw from a large pool of local volunteer drivers but they are stretched beyond capacity and simply cannot meet demand. Can Assist calls for an urgent overhaul of the funding and operational structure of our CT offering in rural, regional and remote NSW. The government simply cannot continue to rely on Can Assist as a long-term solution. These service gaps must be eliminated by government. Can Assist operates without any contribution from government and our funds are increasingly being stretched to fill these unmet needs.

**Recommendation 23 – Palliative Care**

Post the 2021 Inquiry, feedback indicates movement in the right direction; for example, the largest rural health district WNSWLHD has more than doubled its palliative care staff from 21 FTE to 50, many hospitals across rural NSW have added and continue to add specialized palliative care beds, and now online end of life package referrals seem to be quickly approved. However, since these improvements started from a very low base, much more work remains to be done. Notably, the landscape is not uniform – our rural communities experience a wide variation in issues and resourcing across the state. Whilst distance remains a key driver of inequity, even some major regional centres appear lacking in areas. Our volunteers, and communities in general, continue to play a key role in driving solutions and filling the gaps.

The genuine choice to die at home remains elusive for many country residents:

[3] The IPTAAS accommodation rebate is $75 a night for the first week and $120 a night thereafter. Six weeks of accommodation + one return trip from Armidale would attract a IPTAAS patient rebate of $4,805 versus 30 return private trips of $2400. This compares to the implicit CT subsidy of just $1,110.

1. Staffing

Critical to any choice to die at home is the availability of a 24-hour face-to-face palliative care or community nursing service. Whilst 24-hour help lines are typically available and play a key role in keeping people in their homes they are no substitute for face-to-face treatment. Community nurses, particularly in small towns, working part time positions feel unable to abandon their community outside of work hours and often continue to provide a service on demand at no cost. Some are mandated to travel outside of their area and others not. Our volunteers and patients have nothing but praise for our health professionals who remain stretched beyond their capacity in many towns.

Not all towns are equal – whilst many have recently cut back their face-to-face palliative hours to weekday business hours (Deniliquin, Tumut, Leeton, Gunnedah for example) other local health districts for example the Illawarra Shoalhaven have actually extendedG their face-to-face hours to a 6am start through to 11pm at night, 7 days a week. Extending the working day and increasing the nursing resources during these hours in this LHD allowed the palliative care teams there to undertake better anticipatory care significantly reducing any need for assistance during the non-face to face period.

Palliative social workers are also covering large areas which logistically restricts visits to sometimes only 1 or 2 patients a day, yet funded positions are typically fractional, which leaves large areas essentially unserved.

2. End of Life packages

The new online application process system has addressed many of the prior issues raised with respect to slow approvals, however services are in critical short supply. In some cases, packages are being rejected outright because providers simply cannot meet demand. At least in some health districts, health professional referrals are restricted to only one approved provider rendering no alternatives or competition for services. Distance is the key problem – many social workers do not even bother applying outside of regional areas. When services are secured, they are typically less than what is needed.

Our Southern Highlands Can Assist branch has teamed up with another locally based charity hospice fund to offer their community real choice in death. Between them they fund the cost of a private palliative care specialist to provide the care they need at home. Should the patient choose to die in hospital and the public facility has no capacity the cost of this is funded (regardless of the insurance status of the patient) with either the local private hospital or the hospice of an Aged Care Facility. Our branch there is currently providing financial assistance to 60 end-of-life patients; they provide funding up to $5,000 to each patient and the community hospice charity funds any further expenses.

Rather than endure the often too slow process of securing a provider through the State Government end of life packages, local public hospitals frequently refer their patients direct to Can Assist or to their palliative care partners where they know services will be quickly provided and funded. If Can Assist, a not-for-profit charity unfunded by the government, is able to forge these partnerships and provide help in a timely manner – why can't our State Government do the same?

3. Equipment Hire

Critical to any death at home is access to various equipment needs; walkers, lifters, showering equipment etc…In some LHDs, like the HNE or WNSW or the Illawarra Shoalhaven these supplies are generally accessed from the public hospital at either no charge or a small hire fee. Notably, charities like Can Assist and others have been instrumental in building up that existing public equipment pool – yet another area that should not be a Can Assist responsibility. In the Murrumbidgee LHD however, there is no such public pool. Here our branches are routinely paying large hire fees for home equipment, for example - $900 for a 3 month hire of an electric bed, $445 dollars for an air mattress and other incidentals. Adding insult to injury the Murrumbidgee LHD remains the only LHD without a major regional public cancer hospital leaving further medical out of pockets for in hospital treatment costs.

4. End of life (EOL) Drugs

As we raised at the initial 2021 Inquiry there are key EOL drugs not currently PBS listed. Midazolam being the most common whereby patients can be spending $30-50 a day on this one drug alone as they near the end. Should a patient choose to die in a public hospital all such drugs would be free of charge. Chemist accounts typically comprise 40% of the total medical assistance Can Assist provides. After a client of ours from Nyngan received a terminal lung cancer diagnosis last year, we funded $4,000 in pharmacy bills over the next 10 months. Such expense is not uncommon for terminal patients who choose to stay at home.

**Recommendation 21 – Out of Pocket Costs for patients of public-private health services**

These financial stressors have been disproportionality borne by residents of the Murrumbidgee LHD – the only Regional LHD without a comprehensive public cancer facility. Thanks to combined efforts of the member for Murray and the member for Wagga Wagga, with strong support and insight from Can Assist, considerable advancements have been made in this area since the 2021 Inquiry. Concession card holders are now able to access both radiotherapy and chemotherapy at the Riverina Cancer Care Centre at no cost, and further, the newly opened private radiotherapy service at Griffith will operate at zero out of pocket costs for all. Importantly, public to private[4] or private to public[5]free radiotherapy services are routinely offered in metro areas in NSW, meaning that reform in this area has corrected a long-standing injustice for the cancer patients of the Riverina.

Whilst the impact of this reform cannot be underestimated – it really is the tip of the iceberg. It leaves out the entire cohort of patients under 67 treating in Wagga Wagga and furthermore it leaves a raft of additional out of pocket costs incurred (regardless of age or concession status) that remain offered only by the private sector in Wagga Wagga. In addition to radiotherapy and/or chemotherapy, a 12-month cancer treatment profile will typically include 10-12 doctors' appointments[6] various pathology[7] surgery[8] and at least two

[4] E.g. Concord public Hospital, Sydney

[5] E.g. St Vincents private Hospital, Sydney

[6] Out of pockets per appointment typically range from between $70-$140

[7] By way of example a recent single bill paid by Can Assist Young was $704

[8] A pensioner client of ours in Tumbarumba is facing a bill of $2858.85 out of pocket for a mastectomy, which we will also fund.

PET scans[9]. These additional costs, where there has been no relief, can easily exceed $10,000 over a 12-month time frame. Can Assist is left assisting a substantial number of clients to ensure they receive their treatment.

Contrast this to a Can Assist client from Moree, who has been receiving treatment in Sydney for a rare blood cancer. Craig has accessed a wide variety of treatments including – ECP / full body radiotherapy/ chemotherapy and stem cell transplants. He has treated at RPA, at the Prince of Wales and at Westmead public and incurred no out of pocket medical costs whatsoever.

The inequities, however, extend beyond the metro-regional paradigm and are also apparent between the regions. Can Assist branches surrounding Wagga Wagga, like Cootamundra, Temora, Leeton, and others spend up to 43% of their overall assistance dollars on out-of-pocket medical costs (excluding pharmaceuticals), whereas Can Assist branches with proximity to major regional public hospitals like Tamworth and Orange for example spend only 11% and 1% respectively of their patient assistance dollars on medical costs.

Where regional centres like Dubbo and soon to be Tamworth have access to public PET scans – most do not. A current client of ours in Young being treated for testicular cancer is required to have a PET scan every three months for the foreseeable future; we have - funded the first two of those scans at a cost of $1035 each. He has many more of these bills on the horizon.

With a new radiotherapy service to be built in Taree next year by a private provider – will this too attract out of pockets? When will our communities in Armidale and Eurobodalla have access to the local radiotherapy that they were promised some 5 years ago now and what pricing structure will they operate under?

Can Assist is regularly told that was it not for us – some patients would simply not be able to afford treatment. For patients unaware of our services – we have no doubt that in some cases, treatment is forfeited.

**Concluding Remarks and Recommendation 5 – NSW Health engagement with local community groups and charities**

Further to recommendation 5, we acknowledge a sincere and ongoing government priority to engage with grassroots community groups and charities like ours to better understand on the ground realities. Not least, these ongoing Portfolio Committee inquiries continue to provide an avenue for Can Assist to have a voice. In addition, the IPTAAS community forum set up post the 2021 Inquiry in our opinion has opened avenues for real and meaningful dialogue with NSW Health. This forum, which meets quarterly is comprised of multiple community members and charity groups, is co-chaired by Can Assist alongside the Regional Division of NSW Health. This forum provides open channel feedback and input from a wide variety of grass roots community groups. Voices are heard and remedies addressed.

Our volunteers continue to bear a considerable load. For the first 6 months of this financial year, client assistance delivered by Can Assist has increased a massive 42% compared to the same period the year prior; the need is great. Whilst Can Assist will continue in our endeavour for equitable access to treatment and care for all residents of country NSW –

[9] The costs of these scans are widely variable, but routinely exceed $500. Many attract no Medicare rebate.

relying on charity for this crucial work is both unpredictable and precarious. Our assistance is broad based, our funds cannot provide everything to everyone. Government is needed to close these gaps.

Yours sincerely,

[redacted]

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**CAN ASSIST BRANCH MAP**