

**Submission
No 390**

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

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Date Received: 13 December 2020

NSW Parliamentary Inquiry into Health Outcomes and Services in Rural NSW.

Access to Rural Kidney (Renal) Services - a patient's perspective

Introduction

My name is Nicole (Nicki) Scholes-Robertson and I am fortunate to live in Armidale NSW. In the October of 2010 I became suddenly unwell and was diagnosed with IgA nephropathy, that was advanced and resulted in me requiring dialysis or a transplant in early 2014. I commenced peritoneal dialysis in the March of 2014 and was lucky enough to receive a living donor transplant from my younger brother on November 18th 2014 at the Royal Prince Alfred hospital in Sydney.

I am writing this submission from many perspectives and thought it best to roll them all into one document. Firstly, from the perspective of having walked through this journey, that is not an easy one to navigate, of dialysis and kidney transplantation. Secondly as the president of the Rural Kidney Association, a not-for profit, charitable association which is based in Armidale that we have recently formed to assist those in rural NSW with kidney disease, from health prevention talks, funding and supporting kidney support groups and to providing supplies for those starting peritoneal dialysis (The Norm Bourke Box)(1). Finally, as a PhD candidate at The University of Sydney where my thesis is "Improving Access to kidney replacement therapy for rural patients", which I am part way through 4 interview studies and a health economics study into the financial hardship of rural patient accessing dialysis and transplantation.

The rate of end stage kidney disease that requires treatment in Australia is on the rise and with about a quarter of NSWs population living outside the major metropolitan areas, there is a rise in rural and remote patients needing to access dialysis and transplantation(2). We also know that with increasing remoteness there is increasing incidence of chronic kidney disease requiring dialysis or transplant in the indigenous population, and the further away distance wise patients are from their Nephrologist the worse the outcome (3). Coupled with all these factors is an increasing centralisation of tertiary medical facilities and services that are able to treat complex patients with CKD, especially those requiring a kidney transplant.

For the purpose of this submission, I am using the WHO Access definition as they have used in the context of gender, equity and human rights. This includes physical accessibility, "is understood as the availability of good health services within reasonable reach of those who need them and of opening hours, appointment systems and other aspects of service organization and delivery that allow people to obtain the services when they need them". Economic accessibility "is a measure of people's ability to pay for services without financial hardship. It takes into account not only the price of the health services but also indirect and opportunity costs (e.g., the costs of transportation to and from facilities and of taking time away from work)." (*WHO, 25 Questions and Answers on Health and Human Rights.*)

Ongoing Issues and Barriers to Access

1. Transportation

- One of the biggest barriers to rural patients in accessing treatment, specialist appointments and allied health to do with kidney disease is the lack of transportation for the ongoing nature of this, which can be in the case of satellite dialysis, 3 times a week for up to 20 years.
- There are significant ongoing costs of petrol (which is often more expensive than in the cities) and limited public transportation options.
- There can be a reliance on interhospital transfers (patient transfers) to get patients to tertiary centres as they have no other way of getting to another facility without these services, which also mean patients must be admitted to hospital for this transfer, an admission that at times is only to get the transport to see a Dr in a neighbouring town.
- Issues of safety with regard to dialysis patients driving themselves to and from treatment in different towns, even though at times they are too unwell to perform this safely. I myself have driven home from Tamworth to Armidale whilst on dialysis with low blood pressure and feeling very unwell but not having any other options to attend an appointment.
- Nursing home patients on dialysis must pay their own taxi fares to and from dialysis which has an impact on their ability to afford medications and other essential care items
- Two people on aged care package in Armidale who attend inpatient dialysis 3 times a week, one requires a carer to assist him to get in and out of the car and to his unit and this means that a significant proportion of their package is spent on transport to and from dialysis, leaving very little for other appointments and essential shopping.
- I's story- one of our friends is long term on dialysis, Indigenous, blind and on a disability pension and unable to drive. He has been unwell lately and requiring emergency trips to Tamworth for procedures to enable vascular access for his dialysis. These trips have been very difficult to arrange with limited transport options (Aboriginal Medical service and community transport) available and it has caused him and the staff assisting him a great deal of distress to try to organise, especially if it is at the last minute which can be unavoidable in some cases.

2. Accommodation

- Limited at rural hospitals for kidney patients as most designated for other disease groups such as cancer, brain injury or paediatric. This can be particularly troublesome for patients wanting to commence home haemodialysis, with some requiring up to 12 weeks away from home with a caregiver.
- For those lucky enough to receive a kidney transplant, significant time away is required to be near to the hospital for post op clinics and follow up at the tertiary hospital (Newcastle, Sydney or Brisbane) and there can be limited options/ very expensive in larger transplanting centres. Patients who receive a kidney pancreas transplant receive funding to cover their accommodation

from federal funding and as such have no out of pocket costs to cover accommodation.

- In rural areas such as Tamworth and Armidale, which are central medical hubs for renal services, there are limited or no bulk billed accommodation options which would be of great benefit to those requiring short to long term accommodation to be close to home dialysis training or require hospital-based dialysis as unable to receive it in their own town.

3. IPTAAS

- The current process of IPTAAS is quite onerous and the paperwork requires a level of literacy that is not easy for a proportion of the population. There are significant delays in receiving the refunds. For my transplant, where I spent 9 weeks in Sydney, it took a further 3 months to receive my claim money into my bank account and it certainly does not come close to covering the out-of-pocket expenditure that is required by rural patients and their families through this time where we have to relocate for a number of weeks/months. There are multiple stories where people do not claim what they are entitled to due to the complexity of the claiming process and the length of time it takes to get money back.
- The process for gaining pre approval for flights for deceased donor transplants is a complicated one that is not understood well by the staff in the IPTAAS offices. Patients do not know when they will get the call but there needs to be a quick and easy process for them to have pre approval and sign off and this to be activated with a flight at short notice so as to be able to be at the transplanting hospital with in the time that is required.
- The rates of reimbursement for patient accommodation per night and per kilometre rates for travel have not been revised for some years, they have remained the same for the last 7 years that I am aware of.
- Inability of caregiver to claim for Kilometres to visit their patient who may be in another centre or in tertiary centre. They are not able to gain reimbursement without the person who is requiring care in the car. For transplantation where patients are away for up to 3 months, or long periods of hospitalisation that are required for patients with chronic kidney disease. The caregiver may not be able to stay away from home due to farm responsibilities or work or children and as such may go up and down to visit. This place increased financial strain as these trips are not claimable under IPTAAS or the families visit less often which can have detrimental impacts on the mental health of the person away from their family

4. Financial burden on patients and their families

- There is a significant burden placed financial on patients and their families to access dialysis and transplantation in the form of out-of-pocket costs, leave without pay taken by carers to assist with attending medical appointment and procedures, gap payments for medical tests and screening to be listed on the transplant list and significant difficulty for very unwell people to get the appropriate Centrelink entitlements at a time when they are most needed.

- Limited availability of Bulk billing general practitioners in some rural locations and with an increased frequency of needs to attend a doctor when you have one or more chronic illnesses, the gap payments can place financial strain on people.
- Rural patients and their families who choose to do a home-based therapy, either peritoneal or Haemodialysis incur costs to set up for home dialysis including but not limited to new water tanks so as to have increased storage (each Home haemodialysis cycle uses 400L of water), grey water system upgrades, recliner chair for using during dialysis. There are reimbursements schemes, but once again the money is required upfront and a lot of rural families are unable to afford this especially coming off the back of drought and fires as we currently are. This means that these patients do not have a choice of modality as their city-based counterparts would. There needs to be a review of the out-of-pocket costs and some way to improve patients access to home based treatments. This was one of the reasons that we started the Norm Bourke Box at Tamworth Hospital.
- The recent change to medications availability for post-transplant patients through the hospital pharmacy to reduce costs of medications has been a wonderful help, saving me personally \$960 a year.
- Patients having to be on Newstart for extended periods as difficulty in accessing the disability payment. We have had one case where the person received a letter to be on a disability payment days after he had died with complications. The family had fought for 3 years for him to be eligible.

Some Quotes regarding the financial strain on rural families requiring dialysis or transplantation.

- “I can’t go back to work; I wouldn’t leave him still cause he’s not safe. We’ve struggled a bit and we have had all this drama with Centrelink.” (Caregiver, 229 Km Nephrologist, 640km to transplant hospital)
- “Its super stressful when you go to an appointment and they say there's an upfront fee that hasn't been mentioned before, because we genuinely don't have the money in our bank accounts.” (Caregiver – 20 yrs. Old who is primary caregiver for her mother on home dialysis)
- “We are still catching up from the past 3 years (dialysis training and transplant), we could not do it without our parents helping. We would have lost our house.” (Patient in is 40's)
- An Armidale patient paid “\$600 Au return trip” by taxi to attend an urgent procedure 125 kilometres away as all other transport options had been exhausted. The same patient spends around \$4500 every three months for top up to care package (in home) and transport to and from appointments and dialysis 3 times a week at her local hospital.

5. Limited satellite dialysis units/ chair availability

- There are some towns in NSW with very limited access to satellite dialysis units. One for example is Tenterfield where the closest units are Inverell (158km), Armidale (189km) or Lismore (158km). This would equate to over 300km a day round trip 3 times a week for patients and/or family to get to dialysis.
- There are a number of times where the units that are available become full and as such are unable to take any new patients to start dialysis, these people then have to start at another dialysis unit which can be over 100kms away. Our current system is not very flexible to open and shut chairs as required and this can place an added burden on families to travel even more.

6. Cost and availability of specialist services

- During our journey with Chronic kidney disease and the resulting need for dialysis and transplantation, there are many specialists that we may need to see especially for the formation of an arteriovenous fistula for dialysis access. We are lucky in our region that a surgeon comes up from RPA once a month to do surgery and reviews in Tamworth, but I understand that this is not always the case throughout NSW.
- Dental is a vital health need for patients who are chronically ill, but it is an essential part of gaining medical clearance to be accepted onto the transplant list for a kidney transplant. A significant number of people struggle to afford the costs of the check up and any dental work that may be required to be on the list, sometimes into the thousands of dollars. Also, there is a mandatory requirement post-transplant that we are seen by a dentist every 6 months and this causes significant strain for some.

7. Need for people to relocate

- Patients living in certain towns where there is no availability of in-centre dialysis, need to relocate to be closer to appropriate care i.e. a town with a dialysis unit, coming at a financial cost and also a social cost in moving to a place with little or no family or friends.

8. Limited outreach transplantation clinics

- In our area the transplant team is only in Tamworth from John Hunter Hospital once every 3 months. This means that there is a delay in patient seeing the transplant team if they are unwell or unable to make that one day that they are at Tamworth, making it 6 months in between visits or the patient needs to go to the tertiary centre. There is still significant travel for some in our areas to get to Tamworth. I believe that this often means there is less focus on getting transplants for patients in rural areas as the staff are so busy with their work of keeping people alive on dialysis.

9. Heavy reliance on “Champions” with in a health service

- Within each of the local services for kidney patients there are “champions” who go above and beyond in their job to ensure that patients receive the best care possible. They also perform duties that are essential but not necessarily picked up by others. Often our staff are overworked and called on to assist with tasks that may not fall into their role but would not happen without their support. At times there is large turnover of staff and also Burn out of those who go above and beyond to keep us well.

10. Need for increased mental health and social support for chronic illness

- The presence of mental health issues within the chronic kidney disease population is significant, as with a lot of other chronic illnesses. There are however limited options for referral for support or do require out of pocket costs to access these. A recent patient who relocated to the city as they felt they had a better chance of receiving a kidney transplant, commented that at their current city hospital there was a psychologist available to see for those with Kidney disease, something definitely not available to us. We have brilliant social workers but they are only part time and cover a large geography and number of patients and are unable to provide significant counselling services.

11. Home haemodialysis training

- Currently there is no home haemodialysis training in Tamworth and the closest ones are Ballina, Newcastle or Sydney which is a long way for people to relocate for up to 3 months. I believe that a mixed model needs to be adopted whereby part (say the last 6 weeks) is done in the patient’s home with their set up. This would enable them to be away from home for a shorter period but also minimise out of pocket costs on these families.

Suggestions for improvement

- Increased availability of bulk billed accommodation services in both rural and Metropolitan areas.
- Increased focus on prevention and education regarding kidney disease and the long-term costs to both health and patients. Education with rural GPs with regard to Kidney care and prevention and when to refer for earlier referral etc
- Health education program aimed at the lower socioeconomic groups and Indigenous
- Revised IPTAAS process and percentage reimbursement- has been the same amount for at least 7 years. Discuss other systems and pre approval or show receipt.
- Increased outreach services – especially transplant nephrologist and teams and AV fistula surgeons
- Further research into extent of out of pocket expenses
- Review of patient transport and alternate models of care to look at options for patients
- Increased uptake and focus on Home dialysis – minimise expenses and assist with flexible training models that are patient focussed- trainer come to patient maybe for

part of the training to limit emphasis on the relocation of the patient and family for long periods of time. Home dialysis minimises the cost to the health department but also helps to empower patients in their care. It also assists to relieve some of the burden on treating patients in centre where there may be a shortage of chair availability.

- Telehealth availability and usage- that this be a priority for our regional centres post COVID
- Planning for future dialysis needs in towns where there are no current dialysis chairs

I look forward to discussing this more fully with you at any stage and thank you for your time spent considering how these services can be improved to assist rural and remote families to have equity of access to care and treatment. We are so wonderfully blessed in this state to have amazing Staff who work in rural areas and provide us with wonderful care with at times limited resources.

Yours sincerely

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