Submission to the Aboriginal Lands Parliamentary Standing Committee

Topic: Community-based dialysis on the Anangu Pitjantjatjara Yankunytjatjara Lands

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Summary

This submission outlines a brief history of key events and initiatives over the past 15 years that have been directed at improving the provision of dialysis services for end-stage renal patients from remote Aboriginal communities in Central Australia, including Anangu communities on the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands.

In reflecting on this 15 year history, it is suggested that all the necessary ingredients were available to provide an appropriate response to the needs of dialysis patients living in remote communities but that a lack of political will and the absence of a genuine commitment to closing the gap in Aboriginal disadvantage served to thwart the realisation of such a much-needed response.

In September 2015, we once again have an ideal opportunity to do the right thing. The current availability of $1.7 million for establishing a permanent dialysis facility in Ernabella/Pukatja on the APY Lands, the willingness of a service provider to coordinate and provide community-based dialysis services, and a responsible and compassionate response from the South Australian Government could all combine to realise a long-held dream, improve people's health and wellbeing, and save lives. The Anangu Lands Paper Tracker Project of Uniting Communities appeals to all those with decision-making powers to not allow this to become another missed opportunity.

Introduction

At the outset, I'd like to thank the Aboriginal Lands Parliamentary Standing Committee for inviting me to share some insights with you about the provision of community-based dialysis on the APY Lands. As many of you know, the Paper Tracker Project of Uniting Communities has tracked and campaigned for dialysis support services and treatment for Anangu from the Lands who are suffering end-stage renal disease and for whom accessing dialysis is a matter of life or death.

Given that access to dialysis is not available on an ongoing basis in any APY community, people needing dialysis have to relocate to cities or large regional towns. These relocations come at great social and cultural cost to the individual, their family and the broader community.

Let's reflect for a moment on why there is a call for a permanent facility on the APY Lands and what the benefits of a community-based model might be, when compared with urban-based or mobile unit dialysing. While some of the benefits overlap, they can be grouped into two main areas – those affecting community and those affecting service providers.

Communities and families

- Families are given the opportunity to look after their loved ones in their own homes
- Patients are invariably happier and healthier if they are able to be at home on country
- Dialysis patients can maintain or gain employment and leadership roles and have a positive role in the lives of their grandchildren and in the cultural life of their community
- There is potential for local employment in support roles and new pathways into health work roles
- There are many more opportunities to demystify dialysis and for well-engaged dialysis patients to educate their families
- Some stable dialysis patients can be home all the time
- There is a sense of local ownership and engagement
- Reduced costs and anxiety about accommodation and transport.

Service providers

- The costs of wear and tear on infrastructure and assets is far lower than that on a mobile facility
- In a community setting, more dialysis treatments can be done and at a much lower price per dialysis treatment
- Renal nurses live in community and can get to know patients; this rapport can improve health outcomes
- There is an increase in patient attendance, improvement in clinical outcomes and a much reduced hospitalisation rate
- There is an end to dialysis patients risking their lives to return to the community without treatment and putting strain on the primary health care service.

A brief history of efforts to improve dialysis services – a series of missed opportunities?

The issues and the debates around the provision of dialysis services in remote communities are by no means new. The call for community-based dialysis and government deliberations about this have been ongoing for many, many years.

I would like to refer this Committee to a timeline (see Attachment One), that is by no means comprehensive but that charts key events and efforts to address renal disease in remote Central Australian communities over the past 15 years. This timeline provides a snapshot of the inordinate amount of time and effort – as well as generous offers of funding – that has gone into attempting to improve dialysis services and infrastructure for people living in remote communities in Central Australia and for Anangu from the APY Lands who are suffering from end-stage renal disease.

To highlight just a few of these events and efforts: Over many years, Anangu renal patients from the APY Lands have sought help and support. As far back as 2001, the Nganampa Health Council on the APY Lands reported that six people from the APY Lands had had to relocate to Alice Springs in order to access dialysis and that this number was ‘expected to grow significantly over coming years’.[1] In order to support renal patients and their families, during 2001, Nganampa employed a Renal Project Officer; this role was viewed as ‘very successful’ and ensured that Anangu on dialysis in Alice Springs were settled into supported accommodation and were able to access social security and support services. Importantly, it also provided ‘transport home to country once a month for these clients so that links with extended family and with community [could] be maintained’.[2] Unfortunately, ongoing funding for this position was not secured.

In 2003, the South Australian ‘Generational Health Review’ highlighted community and client expectations that, in future, the health care system would, ‘deliver services as conveniently as possible to the person, predominantly in a primary care setting, in the home or an easily accessible local facility’. It also called on the South Australian Government to, ‘review the level of investment in programs addressing the quality of life of Aboriginal people and changes in the way services are delivered, with greater emphasis on community, kinship, family and social connectedness’.[3]

In June 2007, some four years after it accepted the Generational Review’s findings, the SA Government launched a new State Health Care Plan that included reforms to the way health services are delivered outside of metropolitan Adelaide. The aim was to provide, ‘more services locally so that country South Australians [would] not have to travel to Adelaide as often for treatment’[4] and that the expansion of dialysis services was an “important feature” of the new State Care Health Plan’.[5]

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[1] Nganampa Health Council, 2001. *Annual Report 2000/2001*, p25.

[2] Nganampa Health Council, 2001. *Annual Report 2000/2001*, p25.

[3] Government of South Australia, 2003, *Better Choices, Better Health: Final Report of the SA Generational Health Review*, piii.

[4] Hill, J. 6 June 2007. “New Plan for Country Health”, media release.

[5] Hill, J. 25 June 2008, “Open letter to Rural Doctors Association from State Government,” media release.

In December 2008, a $1.8 million expansion of the Port Augusta Renal Unit was completed. While this enabled patients from the APY Lands to access treatment in Port Augusta, the distance they were required to travel was further (by an additional 400km) than to Alice Springs – thereby undermining a key objective of the State Health Care Plan and not adequately addressing the needs of Anangu dialysis patients.

Since 2006, Anangu have looked to Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT) to assist them. A notable campaigner, the late Mr McKenzie who was a leader in the Ernabella community and who sadly passed away in 2014, approached WDNWPT asking for help to set up a permanent dialysis facility in Ernabella. WDNWPT helped and gave advice whenever possible, most of which was unfunded by any government department. This support included organising safe travel back to the Lands for dialysis patients from Alice Springs to go home for long weekends, funerals or cultural business, and the 'Purple Truck' was used to provide support to patients. In addition, unfunded support has been provided to APY dialysis patients in Alice Springs through their inclusion in social and wellbeing activities run by WDNWPT's Purple House. WDNWPT also provided technical advice to the South Australia Government when it received Commonwealth funding to set up a mobile renal dialysis unit. Over the years, the NPY Women's Council has also supported and assisted renal patients whenever possible, and has been a key and active partner in the collaboration to improve access to dialysis services.

In 2009, the Federal Department of Health and Ageing told a Parliamentary Inquiry that the level of end-stage renal disease was critical in remote Indigenous areas and that a 'diaspora' of displaced people was being created:

> *We still have high rates of renal disease in other parts of the country, but as you go into remote Australia it is an absolutely critical issue for very large numbers… in some parts of Australia we almost have a diaspora of people who cannot live in community anymore. In some communities nearly everyone over the age of 50 who is alive is either in town or with their partner in town on dialysis*.[6]

Even back in 2009, the evidence was clear – the need for dialysis across remote Aboriginal communities was moving towards epidemic proportions. In the space of about a decade, the number of Anangu from the Lands who were needing dialysis had tripled – from six in 2001 to 18 in 2010, with the current number of Anangu dialysis patients in 2015 being 22.

However, in 2009, in the face of this growing crisis and in an attempt to deal with dialysis capacity issues in Alice Springs, the Northern Territory Health Department 'closed the borders' to any new dialysis patients from South Australia and Western Australia. In response, the Commonwealth, led by the then Minister for Health, Warren Snowdon, commissioned the Central Australian Renal Study (CARS), which was a joint

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[6] Podesta, L (DoHA). 28 May 2009. Transcript of evidence presented to the House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, p4 and p18.

study by the Australian, Northern Territory, South Australian and Western Australian Governments to develop a range of feasible clinical service delivery models and care pathways to best meet the current and projected needs of renal patients from remote Aboriginal communities requiring dialysis in Central Australia. The findings were to inform policy recommendations on the most effective and feasible service delivery options and care pathways for Aboriginal people in need of renal services, including dialysis, and to identify issues regarding the distribution of these services. The final report includes stories from people in remote SA communities and highlighted the issues facing people away from home, family and country, when accessing dialysis.

The CARS Report was presented to parliament in June 2011. It recommended that all renal patients who had support networks in Alice Springs should be allowed to access services there and that additional dialysis services in remote communities or closer to home was warranted. At the time, Amata in SA was suggested as a possible site – there was at the time, an under-utilised substance misuse centre in Amata that was ear-marked for potential use as a dialysis facility.

At the time of releasing the CARS Report, Minister Snowdon offered $13 million for more supported accommodation in Alice Springs and Tennant Creek. Following the release of this report in 2011, governments were unable to agree on how this money should be spent and how services might be accessed and managed – the result was that $3 million was returned to the Consolidated Revenue account and this money was lost to renal patients who were desperately in need of dialysis services.

Before the last Federal election in 2013, Minister Snowdon approached Western Desert Dialysis to develop an alternative plan for the use of the remaining funds, with the intention being to establish dialysis infrastructure in remote WA, SA and the NT. The Minister gave 'in principle' approval for this plan and announced Stage One of the funding. However, the Labor government lost the Federal election and, once again, the money that had been on offer was off the table.

In 2014, the South Australian Government launched its own Renal Mobile Unit, coordinated by Country Health SA. This has been welcomed as a positive response as it has three dialysis chairs and provides respite services that enable A<u>n</u>angu with end-stage renal disease to go home for short visits.

So, while there have been occasional small-scale gains made, in looking at this timeline and the events over a 15 year period, I'd suggest that we have witnessed a number of missed opportunities – opportunities that signalled a confluence of a number of factors, including: an expressed and urgent community need; offers of significant funding; eager and equipped service providers; access to resources, staffing and expertise; and a reliable evidence base and solid foundation of research (CARS and Ernst and Young report, amongst others) on which to build and provide community-based dialysis.

So, given the availability of all the necessary ingredients, this begs the question: What were the obstacles to providing an appropriate and much-needed response to people with end-stage renal disease living in these remote Aboriginal communities? In short – and leaving aside some of the so-called 'technical' red-herrings that have been thrown up, such as the lack of clean water and a reliable power supply in remote communities – it could be argued that a lack of political will and party-political jockeying and competition is at the heart of why, 15 years on, remote communities on the APY Lands still do not have access to permanent dialysis services on country and why persistent efforts have been thwarted. Ordinary people living with renal disease have become the casualties of shameful bureaucratic and political game-playing and a lack of commitment to genuinely close the gap of Aboriginal disadvantage. For Anangu who are suffering from renal disease, the endless discussions and offers of funding and the ongoing uncertainty as to whether governments and service providers are actually going make dialysis on the Lands a reality, it must feel a bit like ground-hog day. They've been around this track so many times and for such a long time, with their hopes raised by offers of funding and negotiations, only to be dashed by a lack of delivery – many Anangu have been left feeling very disillusioned and sad, while others have died while campaigning and waiting for governments to sort out what is actually a very simple thing.

The current window of opportunity

In early 2015, Western Desert Dialysis was again asked by the Northern Territory and Commonwealth Governments to resubmit plans for the use of the remaining $10 million (that had luckily not been sent back to the Consolidated Revenue account), and a reconfigured proposal was submitted. This included a proposal for infrastructure and capital funding for a dialysis facility in Ernabella/Pukatja.

More recently, in late July 2015, the Federal Assistant Minister for Health, Fiona Nash, made two announcements. The first was that an agreement had been made with the NT Government to spend the original $10 million on accommodation and dialysis infrastructure in remote NT communities. The second announcement included a further $6.3 million directly to Western Desert Dialysis for infrastructure in Ernabella and a number of other remote Aboriginal communities in NT and WA. This funding allocation to Western Desert Dialysis clearly indicates that this organisation has significant credibility and a proven track-record of providing community-based dialysis and support services in remote facilities.

The South Australian Government is currently being invited to respond creatively and compassionately to a proposal for Western Desert Dialysis to establish and provide dialysis services in Ernabella. An amount of approximately $1.7 million has been provided for the WDNWPT to build a permanent dialysis facility and accommodation for renal nurses in Ernabella/Pukatja, and to purchase the equipment needed to provide nurse-assisted dialysis, as well as two vehicles. The proposed facility would have capacity for up to four dialysis machines, enabling 12 patients to comfortably receive treatment on country each week.

In the event that there are concerns raised regarding the potential for an added burden to be placed on existing community health services, such as the Nganampa Health Council, it is acknowledged that these services are already experiencing a number of pressures and are very busy. Such community health services would not be expected to provide services beyond the current basic primary health care services provided to anyone living in their community, with Western Desert Dialysis' experienced dialysis nurses being responsible to treat and manage dialysis patients in the dialysis facility. The renal nurses would be supported by the relevant nephrologists who had been treating the renal patient prior to them returning to the Lands; this allows for continuity of care and clear communication channels.

The SA Government currently pays the Northern Territory Government an amount for each dialysis treatment that is done for each SA patient in Alice Springs. Western Desert Dialysis is proposing that the SA Health Department and WDNWPT negotiate a similar arrangement, which would not require any additional funding or resourcing from SA. In this way, the SA Government would pay only for the dialysis which is provided, and WDNWPT would remain responsible for all staff recruitment, orientation and support, and all clinical services. A similar arrangement has been working effectively between Western Desert Dialysis and WA Country Health for more than a year; there is no reason why a similar arrangement couldn't work in South Australia.

In conclusion

So, what is to be done in light of this new offer of funding for a permanent dialysis facility on the APY Lands? Once again, we have a confluence of all the necessary factors that could make community-based dialysis on the APY Lands a reality. Are the mistakes of the past going to be repeated and the opportunities missed once again or are all the relevant players going to join in a bi-partisan and collaborative effort to realise a long-held dream and do the right thing by sufferers of renal disease in remote Anangu communities?

Renal patients from remote APY Lands communities, Western Desert Dialysis, and all those who have been collaborating and campaigning for community-based dialysis services over many years are currently in a state of suspended animation as we wait to hear whether there is going to be a positive response to the current offer of funding and the proposed model for a permanent dialysis facility on the Lands. Let's hope that reason and compassion prevail, that the strong evidence-base for dialysis on county is recognised, and that there is a favourable outcome for all renal patients – no more renal patients and their families should become part of a disconnected and displaced diaspora and no more lives should be lost as a result of delays and futile deliberations.