



**Ngaanyatjarra Pitjantjatjara Yankunytjatjara  
Women's Council (Aboriginal Corporation)**

7<sup>th</sup> April 2010

Committee Secretary,  
Senate Select Committee on Regional  
and Remote Indigenous Communities,  
Parliament House,  
Canberra  
ACT 2600

By email to: [indig.sen@aph.gov.au](mailto:indig.sen@aph.gov.au)

**Senate Select Committee on Regional and Remote Indigenous Communities**

This submission addresses 1(b) of the Select Committee's Terms of Reference:  
*the impact of state and territory government policies on the well-being of regional  
and remote Indigenous communities.*

**1. Introduction**

Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council  
NPY Women's Council provides the following services to clients in its tri-state  
membership area (*see NPY region map attached.*) These services are provided on  
behalf of the Australian, WA, NT and SA Governments:

- Youth programs including school holiday programs;
- Domestic and Family Violence Service;
- Aged care support (SA only);
- Aged advocacy;
- Disability support and advocacy;
- Carer Respite for carers of frail aged and those with disabilities;
- Child Nutrition and Well-being;
- Emotional and Social Well-being;
- Ngangkari (traditional healers);
- Arts support through its Tjanpi Desert Weavers women's fibre art social enterprise; and
- Emergency relief.

The organisation has an elected Board of Directors and around fifty staff. It comes under the *Corporations (Aboriginal and Torres Strait Islander) Act 2006* (the CATSI Act.)

Patron: Professor Marcia Langton AM

Its Constitutional objectives are to:

- I. Provide a forum for Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara women to discuss their concerns;
- II. assist and encourage the representation and participation of women from the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara region on local, regional and other relevant bodies;
- III. help individual women and girls to achieve further training, education and employment;
- IV. establish, provide and or promote services to improve the health and safety, education and general well-being of people in the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara region;
- V. establish, provide and promote the artistic and cultural interests of Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara women;
- VI. promote and support the achievements and authority of Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara women;
- VII. gather and provide information about issues of importance to Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara women and to the broader community;
- VIII. promote and encourage the law and culture of Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara women; and
- IX. support and encourage other women and organisations who work towards similar aims<sup>1</sup>.

## 2. *NPY Women's Council and renal issues*

NPY Women's Council Directors and members have a long and admirable (thirty-year) record of advocating for people in the NPY cross-border region. They been deeply concerned about the plight of renal dialysis patients from their region for several years, and have made their concerns known, until recently mainly to NT agencies, as Alice Springs has (logically) been the treatment centre for end-stage renal failure sufferers from the tri-state, cross-border area.

Up until early 2009, those concerns were mainly in relation to: the hardships involved in the necessary move long distances from home communities to Alice Springs to obtain treatment (sadly ironic in the current situation); the lack of decent, properly managed housing for renal patients in Alice Springs and the increasing need for such housing with the growing number of renal patients; financial issues; and attempts to prevent or reduce the loss of contact with their community of origin and family through the extremely difficult arrangement of short trips home.

This advocacy is in keeping with object IV of the NPY Women's Council Constitution. A number of NPY members or their spouses or other close family members are, or have been, renal dialysis patients. Several members, who must live in Alice Springs because of their own, or their husband's need for regular dialysis, are very involved with NPY's Tjanpi Desert Weavers' arts social enterprise<sup>2</sup>.

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<sup>1</sup> Further information about NPY Women's Council can be obtained at: [www.npywc.org.au](http://www.npywc.org.au)

<sup>2</sup> [www.tjanpi.com.au](http://www.tjanpi.com.au) and [www.npywc.org.au](http://www.npywc.org.au)

Tjanpi, as well as other regular contact with NPY Women's Council ( including in a couple of cases, as elected Directors) provides these women with interesting and purposeful engagement and helps to make life away from home much more tolerable than it would be otherwise.

The move to Alice Springs for dialysis was described by a renal patient at a meeting convened by NPY Women's Council several years ago as a 'one-way ticket to a coffin.' Imagine the additional stress, despair and dislocation for people – diagnosed with end-stage renal failure – of having to move not just several hundred, but up to 1761 kms. from your APY Lands home community to Adelaide<sup>3</sup> or 1500 kms. from Warburton to Perth, to a hostel room in a strange city with little prospect of getting home even for a visit.

### 3. Past and current renal treatment policy

It is not proposed to go through a complete chronology of events in this submission, mainly due to time constraints and also to avoid repetition. We refer Committee members to the 'Paper Tracker' site of UnitingCare Wesley Adelaide, at the following location, for a comprehensive recent history of Central Australian renal dialysis issues and relevant correspondence<sup>4</sup>.

In January 2009 the NT Government decided to stop accepting end-stage renal failure patients from SA and WA for treatment in Alice Springs, citing an increase in numbers and insufficient facilities. NPY commented publicly at the time on what it believed to be an unfair and cruel decision, and in August 2009 wrote to the respective NT, SA and WA Health Ministers, pointing out, among other things, that:

"The recent decision to force new patients to undergo treatment only in their home state... is likely to make end stage kidney failure even more distressing and unsettling for sufferers."

SA Minister John Hill advised on 16<sup>th</sup> October in his reply to NPY's Acting Co-ordinator Andrea Mason, that a new satellite dialysis unit, due to be completed in early 2010, was being built in Alice Springs, and once open, would enable APY patients: "if clinically appropriate" to "have the option of being treated in a South Australian facility ... or at the new unit in Alice Springs."

The NT Minister Kon Vatskalis was not so confident. On 2<sup>nd</sup> November in his reply to Ms Mason, he advised that: "negotiations are currently underway with SA and WA Health Departments to consider a proposal for the continued management and care of patients in the Central Australian region and to develop comprehensive cross border agreements and partnerships."

The three Ministers met in at the Australian Health Ministers' conference in Adelaide in November 2009, at which time NT Minister Kon Vatskalis announced that he wanted to 'urgently' develop a tri-state agreement for the treatment of renal dialysis patients in Central Australia: "Under the agreement I want Alice Springs to be the hub for renal dialysis treatment across Central Australia – with all states contributing

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<sup>3</sup> Distance from Watarru, APY Lands, to Adelaide.

<sup>4</sup> [www.papertracker.com.au/index.php?option=com\\_content&task=view&id=214&Itemid=1](http://www.papertracker.com.au/index.php?option=com_content&task=view&id=214&Itemid=1)

funding. Mr Vatskalis said the growing demand on renal services by WA and SA patients requiring dialysis has exceeded the Alice Springs Renal Unit's capacity - with 198 patients being treated, including 30 patients from WA and SA. "The NT Government wants to see renal dialysis patients treated closer to where they live, and we have invested millions of dollars over the last four years to expand on renal services in Central Australia<sup>5</sup>."

The issue was again brought to public attention in late 2009 when Patrick Tjungurrayi from Kiwirrkurra in WA faced the choice of going to Kalgoorlie or Perth for dialysis, or remaining at home to die<sup>6</sup>.

#### **4. Campaign to change exclusion policy**

In February 2009, former NPY Women's Council staff member and (later) elected Director, Nura Ward, aged 71, was admitted to the Alice Springs hospital, largely in relation to heart problems. Whilst she was there it was ascertained that her kidneys were failing and she underwent several sessions of dialysis treatment. After a week or so in hospital, she was advised one afternoon that she would be moved to Adelaide the next morning, leaving at 8 am, for continuing dialysis and permanent residence. This decision was reviewed following discussions between Nganampa Health Council Inc. and the hospital. Mrs. Ward eventually had a bit of a reprieve, and went home to Ernabella in mid-March, but before leaving Alice Springs she had a fistula inserted in preparation for when she needs to go on to permanent dialysis. This could occur at any time.

NPY Women's Council advocated strongly on behalf of Mrs. Ward and others from the APY Lands and Ngaanyatjarra Lands WA communities, who are already living, or will soon be forced to 'choose' to live, in towns or cities much further from their homes than Alice Springs, in order to prolong their lives with dialysis. Committee members may be aware of some of the media coverage. Attached are copies of NPY media releases\* and a transcript\* of the ABC's NT Stateline coverage of the issue on 19<sup>th</sup> March. The latter shows the pathetic situation of but two renal patients from the APY Lands recently forced to move to Adelaide<sup>7</sup>.

NPY also corresponded with the NT and SA Ministers and met with SA Health bureaucrats and with the Indigenous Health Minister Warren Snowdon.

#### **5. Governments' responses**

On 13<sup>th</sup> November 2009 the NT Health Minister Kon Vatskalis had also further reminded the public of the amount of money that had been, or was about to be spent, on dialysis, in order to deal with the increase in numbers: "In 2007 the NT Government announced a major new investment in renal services with an additional \$24.4 million over four years to provide improved services. We have also funded construction of a new \$16.7 million, 15-station dialysis renal unit due for completion

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<sup>5</sup> 13th November 2009; media release: *Renal Dialysis on Agenda for Australian Health Conference*.

<sup>6</sup> 'Indigenous artists takes stand on renal ban' ABC PM 3<sup>rd</sup> December 2009:

[www.abc.net.au/pm/content/2009/s2754768.htm](http://www.abc.net.au/pm/content/2009/s2754768.htm)

<sup>7</sup> [www.abc.net.au/news/video/2010/03/19/2851258.htm](http://www.abc.net.au/news/video/2010/03/19/2851258.htm) Other stories may easily be found via, for example, Google.

in Alice Springs next year<sup>8</sup>.” In the meantime renal patients from the APY Lands were headed for Adelaide.

The ABC reported on 12<sup>th</sup> March: ‘The NT has lifted the ban for Western Australian patients after negotiations with that state’s Government and says it is happy to have a similar agreement with South Australia. But the Member for Giles, Lyn Breuer, accuses the NT of discrimination and says it is misinforming the public by saying there is a new deal with Western Australia when there is not. “The Northern Territory Government has not requested anything extra from South Australia to enable South Australian patients to use their service,” Ms Breuer said.’

The ‘agreement’ between WA and the NT to take renal patients in Alice Springs in fact excludes those living in Warburton, the largest community on the Ngaanyatjarra Lands with a population of around 450, and anyone to the west of that community. The tri-state region was thus split again by a border imposed for the convenience of government, to the great detriment of renal patients and their families, and barely anyone seemed to care, or even to notice.

Frustrated with the inconsistent and unsatisfactory responses, NPY Women’s Council wrote to Health Minister Roxon on 10<sup>th</sup> March, urgently seeking Federal intervention in the matter. The letter is attached\* and includes, among other things, some of the confusing and unsatisfactory responses received up to that date. They are also listed as follows:

“The current redirection of people to Adelaide and Perth for treatment is an interim measure.”  
**Kon Vatskalis NT Health Minister. 2nd November 2009. Letter to Western Desert Nganampa Walytja Palyantjaku Tjutaku (Abor. Corp.) (Western Desert dialysis mob)**

“Under the agreement I want Alice Springs to be the hub for renal dialysis treatment across Central Australia – with all states contributing funding.”... “The NT government wants to see renal dialysis patients treated closer to where they live, and we have invested millions of dollars over the last four years to expand on renal services in Central Australia.” ... “We<sup>9</sup> have also funded construction of a new \$16.7 million, 15-station dialysis renal unit due for completion in Alice Springs next year.”

**Kon Vatskalis NT Health Minister. 13<sup>th</sup> November 2009. Media release.**

“Newly diagnosed renal dialysis patients residing in the far north of the state will be treated in South Australia.”

**Government of South Australia, 4th December 2009. Media Release, SA Health**

“WA and NT are now brokering an agreement for WA residents who live west of Warburton to be treated in Alice Springs.”

**Kon Vatskalis NT Health Minister. 24th February 2010. Email to NPY Women’s Council.**

“I want to stress that there is no new deal which has been struck between Western Australia and the Northern Territory.”

**John Hill, SA Health Minister, 5th March 2010. Email to constituent.**

<sup>8</sup> Media release: *Renal Dialysis on Agenda for Australian Health Conference*. We understand the \$16.7 million to be largely Australian Government funding and would like to know what proportion, if any, is coming from the NT.

<sup>9</sup> [The NT? Cth?]

“Whilst we would be happy to have an agreement with SA similar to the one we have with WA this is something that the SA government has to decide.”

**Kon Vatskalis NT Health Minister. 24th February 2010. Email to NPY Women’s Council**

“I am disappointed that you feel the South Australian Government lacks compassion for the APY people needing dialysis; I can assure you that this is not the case; in fact what we lack is right of entry to the Alice Springs Hospital for South Australians who require renal dialysis due to a ban enforced by the Northern Territory Government in February last year.... It is important to note that the Northern Territory Government has not requested anything extra from South Australia, to enable South Australian patients to use their service. I also want to stress that there is no new deal which has been struck between Western Australia and the Northern Territory, in regard to the Northern Territory treating renal patients.

The Northern Territory Government has simply made a decision to exclude South Australian renal patients while continuing to take patients from the remote areas of Western Australia. The exclusion of South Australian patients is most unfortunate.”

**SA Health Minister John Hill: reply to letter from Uniting Church Minister Dean Whittaker 9<sup>th</sup> March 2010.**

There is no avenue for the Commonwealth to intervene. It is up to South Australia to decide how it spends its money. **Warren Snowdon, Minister for Indigenous Health. Position put during meeting with NPY Women’s Council, 3rd March 2010.**

To date (6<sup>th</sup> April) no reply has been forthcoming from Minister Roxon.

On 12<sup>th</sup> March SA Minister John Hill announced an ‘in principle’ agreement with the NT for the NT to provide eight places for SA renal patients and six from WA. (attached\* media release somewhat disingenuously entitled: ‘*More renal dialysis for patients from the APY Lands.*’)

Given that there are currently sixteen to eighteen Anangu from the APY Lands on dialysis in Alice Springs, this will actually mean a reduction. It also appears that the number of WA patients is to be capped at six. When an SA renal patient dies (or gets a transplant – a rare occurrence) their place will go and this will continue until there are only eight left. It seems that WA patients can come so long as there are no more than half a dozen and provided they are not from Warburton or west of Warburton.

## **6. Summary**

The contradictions and obfuscation displayed by the States and NT on this issue are nothing short of disgraceful, capped by the SA Government’s proud pre-election announcement that it will actually reduce the number of Alice Springs places currently available to renal dialysis patients. The Australian Government’s reluctance to become involved, in our submission, casts it also into a poor light. Whilst we acknowledge the additional expenditure to date, it remains the case that people are being forced to move much further from home for this treatment than is reasonable. Governments must surely be judged on how they treat the most needy, and in this instance all are failing the test.

The renal epidemic is not new and whilst it is true that the number of patients has increased, this is surely not unforeseen. The APY Lands primary health care service Nganampa Health Council Inc. has recently advised NPY that there are around twenty people soon to go on to dialysis from the APY Lands. Community-based dialysis on the APY Lands is a very long way off, and may never happen. Nganampa has acknowledged the enormous difficulty of this and the SA Government has been less than honest, and has raised false hope by suggesting that it is under serious consideration. The 'dialysis truck' to be supplied by the Jimmy Little Foundation, reportedly by the end of this year, will not it seems assist SA patients<sup>10</sup>.

The lack of housing and or supported accommodation for end-stage renal patients is of great concern. Of the current 160 patients on dialysis in Alice Springs, 80 do not have permanent housing. This undoubtedly would negatively affect health outcomes. This figure does not take into account the total number of other family members who have moved as a result of patients' relocation. A significant investment in additional, supported and well-managed housing is needed for renal patients in Alice Springs.

As Senator Scullion told ABC's Stateline on 19<sup>th</sup> March: "We really are in a lot of strife on this matter. We've known it's been coming for at least a couple of years, simply because of people coming from the APY Lands, coming from Western Australia and simply arriving in Alice Springs and needing dialysis. This is a life saving, daily life saving treatment, you can't turn people away." Unfortunately, that is precisely what is happening.

## 7. **Recommendations**

We submit the following recommendations for consideration by the Committee:

1. That the Minister for Health Nicola Roxon meets with State and NT Health Ministers as a matter of urgency, in order to ascertain how APY Lands and Ngaanyatjarra Lands end-stage renal patients from Warburton and west of that community, who so choose, can be treated and accommodated in Alice Springs as soon as possible.
2. That the Australian Government examine how the States and the NT might best apportion funds provided by the Australian Government in order to achieve 1.
3. That Minister Roxon and her Ministerial colleagues take whatever action is open to them to ensure that the above-mentioned renal failure sufferers may have the option of treatment in Alice Springs.
4. That the Australian Government's examination of how the States and the NT might best apportion funds provided by the Australian Government in order to achieve 1., include funding for additional housing and supported accommodation for end stage-renal patients in Alice Springs.

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<sup>10</sup> [www.theaustralian.com.au/news/health-science/dialysis-truck-treats-remote-aborigines-medicines-australia-and-the-jimmy-little-foundation/story-e6frg8y6-122584550765](http://www.theaustralian.com.au/news/health-science/dialysis-truck-treats-remote-aborigines-medicines-australia-and-the-jimmy-little-foundation/story-e6frg8y6-122584550765)

5. That the Australian Government immediately conduct or commission research in order to investigate the treatment options and estimates of costs to allow end-stage dialysis patients treatment in their home communities or access to respite dialysis to facilitate short-term visits.
  6. That the Australian Government immediately conduct or commission research in order to obtain the best possible estimates of the number of people from the NPY tri-state region likely to become end-stage dialysis patients needing treatment outside their home communities over the next ten years, in order that their treatment may be administered as close to their home communities as practicable, without the need to travel to far distant regional or capital cities.
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