# SECOND SUBMISSION TO THE SENATE SELECT COMMITTEE ON REGIONAL AND REMOTE INDIGENOUS COMMUNITIES

## UnitingCare Wesley Adelaide

**26 March 2010**

## Introduction

UnitingCare Wesley Adelaide (UCW Adelaide), an agency of the Uniting Church in Australia, is a South Australian community service organisation with over 100 years experience in providing services to low income and disadvantaged people.

In February 2009, UCW Adelaide provided a written submission to the Senate Select Committee on Regional and Remote Indigenous Communities. Subsequently, at the invitation of the Committee, UCW Adelaide gave formal evidence to the Inquiry at a public hearing held in Adelaide on 4 March 2009.

This second submission to the Inquiry provides evidence in relation to the Committee's second term of reference:

(b) the impact of state and territory government policies on the wellbeing of regional and remote Indigenous communities.

This submission focuses on the way government policies are impacting negatively on the well-being of Aboriginal people with end-stage renal disease and, more broadly, on their families and communities.

UCW Adelaide would be happy to provide further oral evidence on this issue at the Committee's invitation.

## Overview

Chronic renal disease affects a growing number of people living on South Australia's Anangu Pitjantjatjara Yankunytjatjara (APY) Lands.

Over the last five years, the number of people from the APY Lands on dialysis has doubled: from 12 patients in April 2005 to at least 24 patients in March 2010. This number is expected to climb above 40 by the end of 2011.[1]

Until recently, if a person from the APY Lands required regular dialysis, they would – in most cases – relocate to Alice Springs.

In early 2009, the Northern Territory Government announced that it could not accept any more dialysis patients from the APY Lands or Western Australian remote Aboriginal communities. At the time of this announcement, 18 people from the APY Lands were receiving ongoing dialysis treatment in Alice Springs.[2]

The Northern Territory Government's decision has forced a number of Aboriginal renal patients and their families to move much further away from their home communities than would previously have been the case (*see* Appendix A).

As of 30 November 2009, at least four patients from the APY Lands had been redirected to South Australia for dialysis treatment.[3] The geographic dislocation of these patients has made it is all but impossible for them to return to their traditional lands for significant cultural events, including funerals.

**UCW Adelaide believes that people with end-stage renal disease should be able to access dialysis as close as possible to their home community including from dialysis units located in another state or territory. We would welcome a recommendation from the Select Committee urging the South Australian and Northern Territory Governments to come to an arrangement so that people from the APY Lands needing renal dialysis can obtain that treatment in Alice Springs.**

UCW Adelaide recognises the cost and complexities involved in responding to the rapid rise of kidney disease across Central Australia. We believe recent experience suggests that this type of complex problem is best addressed through a fully coordinated, tri-state approach (much like that employed during the successful roll out of Opal fuel across Central Australia).

**UCW Adelaide believes the Federal Government needs to take the leading role in developing and implementing a comprehensive, properly funded, cross-jurisdictional plan to manage kidney disease across Central Australia. We would welcome a recommendation from the Select Committee to that effect.**

## Responses to the Northern Territory's policy change

The Northern Territory Government's decision to close its border to future dialysis patients from the APY Lands is of considerable concern to many Anangu (Pitjantjatjara and Yankunytjatjara peoples). In recent months, some of these people have raised this matter directly with State and Commonwealth Government Ministers and other Members of Parliament. For example:

***Leonard Burton*** is an Anangu man. He comes from a small homeland near Amata, a community on the APY Lands 20 kilometres south of the Northern Territory border. On 2 February 2010, Mr Burton wrote to the South Australian Minister for Health (Hon John Hill MP). In the letter, he described some of the difficulties and alienation he has experienced since relocating to Adelaide for dialysis:

> I am writing because I have a problem with my kidneys. I have had to leave my country and my people to come down to Adelaide because I am on dialysis. There is no dialysis machine in the APY Lands and we cannot go to Alice Springs any more for dialysis...
>
> When we go on dialysis we have to leave the APY Lands. We have to go and be strangers a long way from our own people and our own country. We feel sad being such a long way from our country. Everything is different and we feel like we are losing our culture...
>
> Up in the Lands people respect me. People listen to me. But down here I feel lost. I feel like important things in my life are slipping away. If I was able to be up in [the] Lands and on dialysis it would be different…
>
> Down here it is hard for everything. We don't know how to live in the city, it is so different. I feel the government workers don't respect me and keep telling me I'm doing the wrong thing. Instead of getting to know me [it seems] like they just think I'm a problem.[4]

***Colin Brown*** is an Anangu man from Pukatja. His wife has end-stage renal disease. In November 2009, Mr Brown wrote to the Federal Minister for Indigenous Affairs (Hon Jenny Macklin MP):

> My wife, Yayimpi, is on dialysis, so we are living in Adelaide, a long way from our home country…
>
> The Alice Springs Hospital says they cannot provide dialysis for people from the APY Lands because they say the APY Lands are in a different State, not the Northern Territory … they say "no" if we are on one side of a line on a map and "yes" if we are on the other side. For us Anangu, our families and our lands cross over the lines that whitefellas have made for the State and Territory borders…

> I know quite a few Anangu who are on dialysis or soon will be. They cannot go to Alice Springs. They will be stuck here in Adelaide too. For the rest of their lives they have to be near the dialysis machine. They will need their families to come down to Adelaide too…
>
> If we had a renal unit in the APY Lands people could still live in their communities and on their country and have dialysis. Families would not have to move a long way away from their own places. Maybe to start off on dialysis they would still have to go to Alice Springs or Adelaide, but then they could come home and have dialysis in the APY Lands.[5]

***Fayeanne Jones*** lives and works in the APY community of Pipalyatjara. In March 2010, she described her experience in a letter to State and Federal Members of Parliament:

> Recently [my partner] went to Adelaide to be with and help his father who, just three weeks ago, went on dialysis. There are lots of Aboriginal people in Alice Springs and Adelaide who are from the APY Lands on dialysis. They feel home sick and want their families more than ever and are always ringing them. … Instead of going to towns or cities why not build a hospital for dialysis patients on the lands…
>
> My mother lives in Perth W.A. and has been on dialysis, for about eight years. She always talks about being in her own country and eating healthy bush food, and being with us, her family. I [have] been travelling backwards and forwards up and down between Perth and Pipalyatjara for eight years now … I really wish they would have some dialysis machines in remote areas.[6]

A number of key Aboriginal organisations have also criticised the Northern Territory Government's new access policy and called for it to be reversed or alternative arrangements to be put in place.

For example, the Aboriginal Medical Services Alliance Northern Territory (AMSANT) has argued that "sending people from remote communities to Perth or Adelaide is creating enormous psycho-social impacts on individuals, their families and their communities" and that some people have refused treatment "so they can go back to their country to die." This is, AMSANT has noted, "an intolerable situation."[7]

The Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council has also expressed its "extreme distress" at the impact that the policy is having on renal patients across Central Australia. In August 2009, in a letter to the South Australian Minister for Health (Hon John Hill MP), the Council noted that the 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 suffers.[8]

## Access to dialysis services in South Australia

The introduction of the Northern Territory Government's new access policy has coincided with the expansion of dialysis services in non-metropolitan South Australia. This expansion is occurring, in part, in response to the findings of a comprehensive review of the State's health care system.

Completed in 2003, the 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."[9]

The Generational Health Review 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.[10]

In June 2007, some four years after it accepted the review's findings, the South Australian Government launched a new State Health Care Plan that included reforms to the way health services are delivered outside of metropolitan Adelaide.[11] According to the State Minister for Health (Hon John Hill MP), these reforms aimed to provide:

> more services locally so that country South Australians [would] not have to travel to Adelaide as often for treatment.[12]

On 25 June 2008, the Minister reiterated this commitment in an open letter to South Australia's Rural Doctors Association:

> We are … committed to repatriating services to the country from the city… We want to ensure that as many people as possible receive treatment closer to home and avoid the need for patients and their support networks to travel to Adelaide.[13]

The Minister also noted that the expansion of dialysis services was an "important feature" of the new State Care Health Plan.[14]

In December 2008, a $1.8 million expansion of the Port Augusta Renal Unit was completed. The redeveloped unit was officially opened by Minister Hill on 23 April 2009 as "another example" of the Government's strategy of "putting improved services closer to patients."[15]

The State Government subsequently reported that the expansion of the Port Augusta unit meant:

patients from the APY Lands can now be treated at Port Augusta instead of travelling to Alice Springs for treatment.[16]

**For patients from the APY Lands, however, the facilities in Port Augusta are approximately 500 kilometres further away from their homes than those located in Alice Springs.**[17]

**UCW Adelaide notes that attempts to divert APY dialysis clients from Alice Springs to Port Augusta are clearly inconsistent with the South Australian Government's strategy to make it easier for people living outside of Adelaide to access health services closer to home.**

## Tri-state meeting (December 2009)

On 4 December 2009, representatives of the South Australian, Western Australian and Northern Territory health departments and other parties met to discuss Central Australian dialysis services.[18] From UCW Adelaide's perspective, the results of this meeting were mixed.

On the positive side, the Western Australian and Northern Territory representatives reportedly reached "an exceptionally positive outcome."[19] Specifically, under a new agreement, Western Australian renal patients living east of Warburton would be able to, once again, access dialysis services in the Northern Territory.[20]

Unfortunately a similar arrangement was not established with South Australia. Instead, at the conclusion of the meeting, the South Australian Government noted that it would "not be providing any additional funding to the Northern Territory government" and that "newly diagnosed renal dialysis patients" from the APY Lands would "be treated in South Australia," specifically in Port Augusta, Whyalla and Adelaide. [21]

The Chief Medical Officer of Australia, Professor Jim Bishop, also attended the December meeting. In a letter dated 11 January 2010, Professor Bishop advised UCW Adelaide that the South Australian, Northern Territory and Western Australian Governments had reached an agreement at the meeting "to work together to address the needs of current and future renal dialysis patients in Central Australia."[22]

UCW Adelaide notes that any agreement "to work together" comes:

- more than three years after Professor Bishop's predecessor – Professor John Horvath – convened "a highly productive roundtable in Alice Springs" to examine the delivery of renal dialysis services across Central Australia,[23] and

- more than two years after the Federal Department of Health and Ageing reported that it was "working with the Northern Territory, South Australian and Western Australian health departments to expand and improve current models of service delivery and care for renal patients" and that "a lot of progress" had been made.[24]

In his letter, Professor Bishop also advised the UCW Adelaide that the Federal Government was:

> encouraging and supporting the relevant States and Territory to reach swift agreement on a sustainable long-term solution to the delivery of renal dialysis services in Central Australia.[25]

**UCW Adelaide considers that the social and cultural difficulties Aboriginal people experience when forced to move considerable distances to receive dialysis treatment are well-documented and that any "sustainable long-term solution" must ensure that people from the APY Lands are able to access renal dialysis services in Alice Springs.**

**UCW Adelaide is concerned that recent and ongoing efforts to resolve this issue have tended to generate broad statements about governments continuing to "work together" to solve these problems but limited progress or tangible results.**

## New "in-principle agreement"

On 12 March 2010, the South Australian Minister for Health (Hon John Hill MP) announced that an "in-principle agreement" had been finalised between the South Australian, Western Australian and Northern Territory health departments, under which eight "permanent patients" from the APY Lands would be able to access dialysis in Alice Springs. The Minister indicated that the Labor Government would sign this agreement "without delay" if re-elected on 20 March 2010.[26]

On 15 March 2010, UCW Adelaide met with representatives of the South Australian Department of Health to discuss the proposed agreement and access to dialysis more generally.

In the course of that meeting, the Department confirmed that:

- the agreement did not secure any additional dialysis places in Alice Springs for people from the APY Lands,
- under the terms of the agreement, the total number of dialysis places available in Alice Springs to people from the APY Lands will fall – over time – from 18 to eight,

- as existing patients die or are transferred to another location, their places will be filled by Northern Territory patients,
- this process will continue until the total number of APY dialysis patients in Alice Springs has fallen to eight,
- while no existing APY dialysis patients in Alice Springs will be forced to relocate to South Australia, new patients will – for the foreseeable future – need to relocate to Adelaide, Port Augusta or Whyalla, and
- up to 20 more people from the APY Lands are expected to commence dialysis in South Australia by the end of 2011.[27]

**UCW Adelaide believes that until dialysis is available on the APY Lands, the South Australian Government should be working to maintain, at a minimum, all of the 18 positions in Alice Springs currently occupied by patients from the APY Lands and that 10 of these positions should not be returned to the Northern Territory Government as intended under the proposed agreement.**

## Dialysis on APY Lands: exploring the options

For many years, Anangu have been calling for dialysis services to be established on the APY Lands.[28] These requests have become more pressing since the Northern Territory Government changed its access policy.

In February 2010, the South Australian Government announced that it was examining "how renal dialysis might be offered on the APY Lands in a safe and sustainable way." The Government noted that it would be "completely guided" by what the Nganampa Health Council believes "is the best approach."[29] On 24 February 2010, the NPY Women's Council labelled this undertaking "a mere distraction from the immediate crisis."[30]

On 15 March 2010, UCW Adelaide raised this matter with the Chief Executive of the South Australian Department of Health (Dr Tony Sherbon). On that occasion, Dr Sherbon confirmed that it would be very difficult and costly to establish and maintain dialysis services on the APY Lands and that any such facility would take many years to establish.[31]

Dr Sherbon also noted that Nganampa Health Council's Medical Director (Dr Paul Torzillo) does not support the establishment of dialysis services on the APY Lands and underscored the Minister's earlier remarks that any such services would not be established without Nganampa Health Council's support.[32]

UCW Adelaide is concerned that recent statements by the South Australian Government about the possibility of establishing dialysis units on the APY Lands

may have prematurely raised the hopes and expectations of Pitjantjatjara and Yankunytjatjara peoples.

**UCW Adelaide recognises the obstacles and costs associated with establishing dialysis services on the APY Lands. We also recognise the likely benefits. UCW Adelaide believes the Federal Government should fund an independent examination of the comparative benefits and costs of providing renal dialysis and accompanying support services for Aboriginal people in a variety of locations including on their traditional lands, in regional centres and in capital cities like Adelaide. We would welcome a recommendation from the Select Committee to that effect.**

# REFERENCES

[1] *See:* Masters, C (Nganampa Health Council). 29 April 2005. Email to Aboriginal Lands Parliamentary Standing Committee, Parliament of South Australia; Gorham, G (NT Dept of Health and Families). 15 March 2010. Email to J. Nicholls (UCW Adelaide); Sherbon, T (SA Health). 30 November 2009. Letter to Rev. P. McDonald (UCW Adelaide); UCW Adelaide. March 2010, "Record of meeting between SA Health and UnitingCare Wesley Adelaide held on 15 March 2010", p3.
[2] Gorham, G (NT Department of Health and Ageing). 15 March 2010. Email to J. Nicholls (UCW Adelaide). UCW Adelaide understands that at the time that the Northern Territory's access policy changed, only two people from the APY Lands were receiving dialysis in South Australia. On 7 December 2009, UCW Adelaide asked the South Australian Department to confirm that this was the case. As of 24 March 2010, this confirmation had not been provided.
[3] Sherbon, T (SA Health). 30 November 2009. Letter to Rev. P. McDonald (UCW Adelaide).
[4] Burton, L. 2 February 2010. Letter to Hon John Hill MP.
[5] Brown, C. 8 November 2009. Letter to Hon Jenny Macklin MP.
[6] Ms Jones' letter was composed in early March 2010. UCW Adelaide understands that copies of this letter were sent to, among others: Hon John Hill MP, Mr Rowan Ramsay MP and Ms Lyn Breuer MP.
[7] AMSANT. 3 November 2009, "Deaths in the Desert Must Stop," media release. *See also:* Northern Territory Council of Social Service. 29 October 2009, "Kidney Crisis threatens lives," media release.
[8] Mason, A (NPY Women's Council). 5 August 2009. Email to Hon. J Hill, SA Minister for Health.
[9] Government of South Australia, 2003, *Better Choices, Better Health: Final Report of the South Australian Generational Health Review*, pxiii.
[10] ibid, piii.
[11] Hill, J. 6 June 2007. "New Plan for Country Health", media release.
[12] ibid.
[13] Hill, J. 25 June 2008, "Open letter to Rural Docs Association from State Govt," media release.
[14] ibid.
[15] Hill, J. 23 April 2009, "New Renal Unit up and running at Port Augusta Hospital," media release. *Also:* SA Health, August 2009, *Renal News: Statewide Clinical Networks*, Issue 4, p1.
[16] SA Health, August 2009, *Renal News: Statewide Clinical Networks*, Issue 4, p1.
[17] For example: Pukatja, the largest community on the APY Lands, is approximately 420km from Alice Springs by road but 1027km from Port Augusta. *See* Appendix A for further information on the distances between APY communities and the renal dialysis units located in Alice Springs, Port Augusta and Adelaide.
[18] Government of South Australia. 4 December 2009. "Northern Territory Renal Services," media release.
[19] Vatskalis, K. 10 December 2009. "Positive Outcome for Central Australian Renal Patients," Northern Territory Government, media release.
[20] ibid.
[21] Government of South Australia. 4 December 2009. "Northern Territory Renal Services," media release.
[22] Bishop, J. 11 January 2010. Letter to Rev. P. McDonald (UCW Adelaide).
[23] Horvath, J. 2007. "Chief Medical Officer's Report" *in* Federal Department of Health and Ageing, *Annual Report 2006-7*, p13.
[24] ibid.
[25] Bishop, J. 11 January 2010. Letter to Rev. P. McDonald (UCW Adelaide).
[26] South Australian Labor Party. 12 March 2010, "More renal dialysis for patients from the APY Lands," news release.
[27] UCW Adelaide. March 2010, "Record of meeting between SA Health and UnitingCare Wesley Adelaide held on 15 March 2010," p3. Available at: http://www.papertracker.com.au/pdfs/SAHealth1.pdf. On 25 March 2010,
[28] For example, in the first half of 2006, Wiru Palyantjaku - an Anangu Task Force charged with identifying service delivery needs and targets – called on the government "to seek funding for the provision of dialysis machines" on the APY Lands by 2011 so that "people get treated locally" (Wiru Palyantjaku, 2006, "Priority Areas Workshop," draft document, p14).
[29] Hockley, C (Office of the SA Minister for Health). 23 February 2010. Email to Rev. D. Whittaker (Uniting Aboriginal and Islander Christian Congress). *See also:* South Australian Labor Party. 12 March 2010, "More renal dialysis for patients from the APY Lands," news release.
[30] NPY Women's Council. 24 February 2010, "*Real people - not just goners. Renal disaster needs leadership and action*," media release.
[31] UCW Adelaide. March 2010, "Record of meeting between SA Health and UnitingCare Wesley Adelaide held on 15 March 2010", p2. Available at: http://www.papertracker.com.au/pdfs/SAHealth1.pdf. On 25 March 2010,
[32] ibid.