

It's no life for an old lady. Remote renal patient told: <u>"Go to Adelaide or go home to palliative care."</u>

Media release



Nura Ward & her niece Melissa Thompson, Alice Springs Hospital 22.2.10

A grandmother and respected senior community member from Ernabella on the A<u>n</u>angu Pitjantjatjara Yankunytjatjara (APY) lands in South Australia's far northwest with kidney failure has been told she must choose between a permanent move to Adelaide for renal dialysis – 1400 kilometres from her community - or go home to die.

Nura Ward is about to become the latest victim of a year-long government policy that denies dialysis treatment in Alice Springs to new renal patients from remote parts of SA, even though Alice is much closer to their home communities. Several Anangu (Aboriginal people) from the Lands have been moved to Adelaide since the policy took effect in January 2009.

Mrs. Ward, in her seventies, is a former cattle station worker; a health worker with her local APY health service, Nganampa Health; and an aged and disability advocate for several years and then an elected member of the NPY Women's Council board. She campaigned vigorously against petrol sniffing and for the wide regional distribution of Opal low octane fuel. A highly accomplished dancer and cultural interpreter in the traditional style of her region, in the late 1990s she instructed the Sydney-based Bangarra Aboriginal dance troupe.

She also has heart problems and is diabetic. Mrs. Ward was admitted to the Alice Springs Hospital just over two weeks ago. In that time it has been ascertained that she now also has serious kidney problems. She has been living part of the time in a house at Ernabella, and part at an aged care facility in that community. She now faces living out the rest of her days in a hostel room or aged care home far away from anyone or anything familiar. "It was bad enough when people had to go on dialysis and live in Alice Springs, but this is much, much worse. We might never see Nura again. She came in to hospital and now they want to shift her to the city, to Adelaide. That's a very cruel thing, especially for an old lady," said her niece Melissa Thompson. "I bet this wouldn't happen to Mike Rann or Paul Henderson or Warren Snowdon's mum, or aunty, or nana."

"What will she do there – with no family, no arts centre with other women around, no close friends? Will she sit in a room by herself waiting to get hooked up to the machine every few days? She might finish up even quicker when we can't visit her. At least in Alice there are other renal patients and patients' wives - some relatives and childhood friends from her country. She'll be lost and lonely like the others who have to live far away for dialysis."

"She is upset and doesn't want to go. But it's not just about Nura. This is happening to Anangu from the Lands because governments can't work out how to provide services and accommodation properly for these people with kidney failure. Can't they see them coming? Can't they count? It's been happening for years but they don't listen – don't increase the services or housing enough. Now they get this choice - go to Adelaide or go home and get ready to die."

The NT Health dialysis facilities are full up and NT Health will not accept any new SA patients. The SA government is increasing its facilities and supposedly also entering into an agreement with the NT, but the policy remains, and SA people continue to have to make a cruel choice.

Additional Commonwealth funds to the NT are used only for NT patients. A planned new facility in Alice is already 'booked up' for NT renal patients. End-stage renal patients from remote SA communities continue to be subjected to a doubly harsh blow – the rest of their life 'on the machine' isolated from their country and families.

"We need a more caring and a fair dinkum regional approach to this – like we've now got with cross-border policing and the justice system under the new tri-state laws in Central Australia," said Melissa Thompson.

"This cutting people out by State borders is rubbish. SA says it's still talking to the NT, but it's more than a year and nothing has really changed. People still have to live so far from home. The idea of living in Adelaide is like moving to Mars for many Anangu."

For more information or to contact Mrs. Ward or Melissa Thompson please ring: Andrea Mason, A/Co-ordinator, NPY Women's Council: 08 89582319; 0439 684 225 andrea.mason@npywc.org.au

Note: Ernabella is 1397 kms. or more than twenty hours from Adelaide by road, but much closer - 480 kms. - to Alice Springs. SA renal patients living in Alice are able to go home for occasional visits between regular dialysis treatments. They typically share hostel accommodation with their spouse if they have one. The Topsy Smith Hostel in Alice Springs, for example, caters solely for renal patients and their spouses/carers.

Photos attached in jpg format. NPY Women's Council website: www.npywc.org.au

Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council (Aboriginal Corporation)

www.npywc.org.au



<u>Media Release</u> <u>Real people - not just goners. Renal disaster needs leadership and action.</u>



Nura Ward, Alice Springs Hospital Mrs. Ward, aged 71, with heart problems, diabetes and kidney disease, has been told she must either move to Adelaide, 1400 kms. from her community, for renal dialysis, or go home to Ernabella on the APY Lands in SA for palliative care.

<u>Media Release</u>

NPY Women's Council says the Federal Government must intervene immediately with South Australia and the NT to sort the disastrous situation of renal dialysis treatment in the Central Australian region.

"Let's be very clear:

- this is a regional, tri-state issue and the lives of people with renal disease are difficult in the extreme, but they are not worthless and should not be mucked about with on the basis of state and territory borders;
- additional renal facilities and accommodation need to made available immediately in Alice Springs for Nura and for other APY Lands dialysis patients;
- SA and the NT have to date shown themselves unable or unwilling to resolve the matter in a sensible and compassionate way," said NPY's acting Co-ordinator Andrea Mason.

"Warren Snowdon is the Minister for Indigenous Health, Rural and Regional Health and Regional Services Delivery. Aboriginal health is funded by the Commonwealth. Warren needs to get in there with his boss Nicola Roxon, NT Chief Minister Paul Henderson and SA Premier Mike Rann and fix this now, for Nura Ward and others from the APY Lands.

There are already 5 or 6 renal patients from SA in Adelaide, and 20 or more on the way. What is the financial as well as emotional cost compared to accommodating

Patron: Professor Marcia Langton AM

them in Alice? Do governments think that because these people have end-stage renal failure they are goners anyway, to be shunted quietly off to isolation from family and country, loneliness, confusion and despair in a big city?"

The SA Government's so-called 'commitment' to a dialysis unit on the A<u>n</u>angu Pitjantjatjara Yankunytjatjara (APY) Lands in the State's far north-west is a mere distraction from the immediate crisis¹.

The SA Government has already shown major incompetence in the operation of a (capital Commonwealth-funded \$2M) substance misuse facility at Amata that it has not been able to staff properly, and which is grossly under-used with no residential program, despite shocking levels of cannabis and grog use in the area. Now it might just turn it into a renal unit. Pigs might fly and Paris Hilton might grow a brain too, but don't hold your breath. It's a long way off and it may never happen. Where will the specialist staff come from? NT Health already struggles to recruit them in major centres.

As for the agreement said to be in progress between SA and the NT where is it and what's in it? Will it be like the one between WA and the NT, announced this week? That deal excludes renal patients from Warburton, the largest community on the Ngaanyatjarra Lands and everything to its west, thus imposing yet another border and forcing those kidney failure patients to go to Perth or Kalgoorlie².

"At least the SA Liberal Opposition has a policy to negotiate an agreement with the NT to allow people from the APY Lands to have renal dialysis in Alice Springs, and not be forced to move to Adelaide or Port Augusta.

So we've got the NT Health Minister Kon Vatskalis flatly refusing to take any more SA patients; and the SA Government - about to go to an election it may well lose - stalling on an agreement with the NT and making vague murmurings about a renal unit out bush.

This needs leadership and Commonwealth and SA and NT co-operation, forced if necessary, and fast. These are real people, sick people - they are not just faceless health statistics.

"Rann, Henderson, Snowdon and Roxon need to get on the job now."

Contact: Andrea Mason, A/Co-ordinator or Chairperson Margaret Smith NPY Women's Council:

Note: Ernabella is 1397 kms. or more than twenty hours from Adelaide by road, but much closer - 480 kms. - to Alice Springs.

¹ www.abc.net.au/news/stories/2010/02/24/2828504.htm.

² www.abc.net.au/news/stories/2010/02/23/2827812.htm.

Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council (Aboriginal Corporation)



Media Release

Who are they kidding? Pollies pass the parcel while renal patients are exiled.

The Prime Minister reckons that any Premier who believes the public is happy with health care services is 'kidding themselves.' NPY Women's Council says the PM is spot on, and Mr. Rudd must now show that he really means it. As with the insulation debacle, he needs immediately to ensure an end to the bickering and buck-passing over the treatment of end-stage renal patients who are forced to move more than 1400 kms. from their remote home communities to Adelaide, rather than receive treatment in Alice Springs. They don't have time to wait and see if the Government's proposed new health regime will get the nod.

"Just have a look at these contradictory comments* from SA and NT Health Ministers, and the position of Warren Snowdon, Federal Minister for Indigenous health," said Andrea Mason, Acting Co-ordinator of NPY Women's Council.

"Vatskalis' and Hill's ducking and weaving and shifting positions are contemptible and speak for themselves. As for Minister Snowdon, he doesn't so much duck as turn his back. The Commonwealth funds this treatment, including the extension of renal services currently underway in Alice – now it seems to be used for NT and some WA residents - so how he can maintain it can do nothing is a mystery. It's high time his boss Nicola Roxon and also Jenny Macklin got involved, because this disgraceful state of affairs has gone on for more than a year."

"These people are sick and they are being treated with contempt because they don't live in marginal electorates. They have limited life spans on dialysis anyway (mean average five years.) Nura Ward is next in line and she is elderly (71 years), ill, and extremely apprehensive about being the next pawn in the cross-border bickering game."

"Say what you want about the wisdom or otherwise of Tony Abbott's bush bash last week, but at least he had the decency to drop in to the hospital room of a sick, scared old lady whom he'd met as Health Minister while addressing petrol sniffing through the provision of the highly successful low octane Opal subsidised fuel. That's more than Minister Snowdon has managed." *"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)

"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

"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

"The Northern Territory Government has simply made a decision to exclude South Australian renal patients and that is very unfortunate. The Northern Territory has not requested anything extra from South Australia, to enable Southern Australian patients to use their service."

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

There is no avenue for the Commonwealth to intervene. It is up to South Australia to decide how it spends its money.

Warren Snowdon, Commonwealth Minister for Indigenous Health, 3rd March 2010. Position put by Minister Snowdon during meeting with NPY Women's Council.



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

<u>Social exclusion: SA State member challenged on renal crisis:</u> <u>Labor must match Liberals' promise</u>

<u>Media Release</u>

NPY Women's Council has questioned **Lyn Breuer**, the SA member for Giles*, on her efforts to resolve the renal dialysis crisis for her constituents on the Anangu Pitjantjatjara Yankunytjatjara Lands in the far north-west.

"Lyn Breuer might have been sitting pretty on a solid margin since 1997, and A<u>n</u>angu votes in the north-west mightn't add up to much numbers-wise, but she is still obliged to represent and stick up for her constituents," said Andrea Mason, NPY Women's Council Acting Co-ordinator.

NPY is disappointed that the Rann Government has been unable or unwilling to negotiate an agreement. The Rann Government's failure on dialysis treatment is at odds with its broader commitment to *social inclusion*. Forcing people from remote communities to move to Adelaide excludes, socially and culturally, some of South Australia's most disadvantaged citizens.

South Australian Shadow Health Minister Dr. Duncan McFetridge has promised that if elected on 20th March, the Liberals will negotiate an agreement with the NT Government so that people from the APY Lands can once again obtain dialysis treatment in Alice Springs. Labor must match this promise.

"We want to know what Lyn Breuer is doing to change the current, harsh and unfair policy that dictates that APY Lands residents - other than around 14 'lucky' ones who got there before January 2009 - cannot receive renal dialysis treatment in Alice Springs. These people, sometimes elderly and all with limited life spans, have been forced to up sticks and move to Adelaide if they want to survive. There are now several who have come under this cruel regime, and probably 20 more on the way," said Ms Mason.

"Lyn Breuer said on ABC radio on 25th February that she was hopeful of a 'commitment' in relation to access to renal dialysis³. What exactly is that commitment?" asked Ms Mason. "Hopefully not just more vague talk about a remote dialysis unit somewhere, sometime. We first need SA to sort facilities in Alice, and quick smart."

NPY Women's Council wants Lyn Breuer to answer these questions by 10th March, before mobile polls are held on the APY Lands and prior to the NPY AGM to be held the following week:

³ www.abc.net.au/news/stories/2010/02/25/2829911.htm

- 1. Do you believe that the South Australian Government should negotiate a new agreement with the Northern Territory Government so that people from the APY Lands needing dialysis treatment can, once again, access those services in Alice Springs? If not, why not?
- 2. Have you advised SA Labor Ministers including Health Minister John Hill of your position on this issue and, if so, when did you do this? If not, why not?
- 3. If you do support the establishment of a new agreement with the Northern Territory, does this include supporting the need for South Australia to provide the Northern Territory with additional funding?
- 4. Have you investigated or will you investigate the situation of A<u>n</u>angu from your electorate who have had to move to Adelaide for dialysis treatment and who say they are facing dislocation and despair at being so far from home?
- 5. Have you spoken to any of these dialysis patients?
- 6. Can you explain SA Labor's apparent inconsistency on this matter? (see below)
 - 16th October 2009: the South Australian Government advised the NPY Women's Council 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."
 - 4th December 2009: 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.
 - 25th February 2010: Minister Hill told ABC radio that the Northern Territory Government had denied South Australian people access to their hospitals but that access had not been denied to WA patients. Minister Hill went on to suggest that NT was "discriminating against South Australia."

Contact:

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Background

In February 2009, the Northern Territory Government introduced a policy whereby no new clients from outside of the Northern Territory would be allowed to use its renal dialysis treatment centres. If a person from the APY Lands needs to go on dialysis, they have to move to Adelaide or Port Augusta.

In December 2009, the Western Australian Government agreed to negotiate a new agreement with the Northern Territory Government so that renal patients living east of Warburton can access dialysis services in the Northern Territory. This arrangement is not completely satisfactory because the renal unit in Kalgoorlie is full, meaning new patients have to move to Perth, and residents of Warburton (pop. 450) and west are excluded.

* Giles electorate statistics:

www.abc.net.au/elections/sa/2010/guide/gile.htm?WT.srch=1&WT.mc_id=Corp_saelection_GoogleAds&gclid=CPKfnrqgn6ACFYQtpAodXQwsag

Note: NPY will hold an ecumenical service on 11th March, World Kidney Day, at the Lutheran Church, Gap Rd., Alice Springs. There will be prayers for a change in policy. See attached flyer or ring 08 89 58 2319 for further details. All supporters and media welcome.

Prayers for Change

"With man this is impossible, but with God all things are possible." Matthew 19:24-26 (NIV)"

Special Ecumenical Service for Renal Sufferers

All Welcome

Please join us to pray for renal dialysis patients and for a change of government policy.

Venue: 2.00pm Thursday 11th March, Lutheran Church, Gap Road Alice Springs.

What if this was your Nana?

Nura Ward, 71, from the A<u>n</u>angu Pitjantjatjara Yankunytjatjara (APY) Lands in SA, has renal and other serious health problems. She is the latest victim of a policy that bars her from having life-saving dialysis treatment in Alice Springs because her home community is in SA. She must go to Adelaide, 1400 kms. from her home, or return to Ernabella for palliative care. Nura is not the only one to face this terrible choice. Others have already had to leave their families and homes, and more will go unless the NT and SA governments show compassion. The Federal Government may have to step in to sort out the arguments that have led to this cruel and unjust situation in the Central region.

Please come to this multi-denominational service to support Nura and other renal sufferers from the tri-state region.

"Where there is no leadership the people fall, but in an abundance of counsellors there is safety. (Old Testament : Proverbs 11:14)"

Supporting World Kidney Day 11th March.

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

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