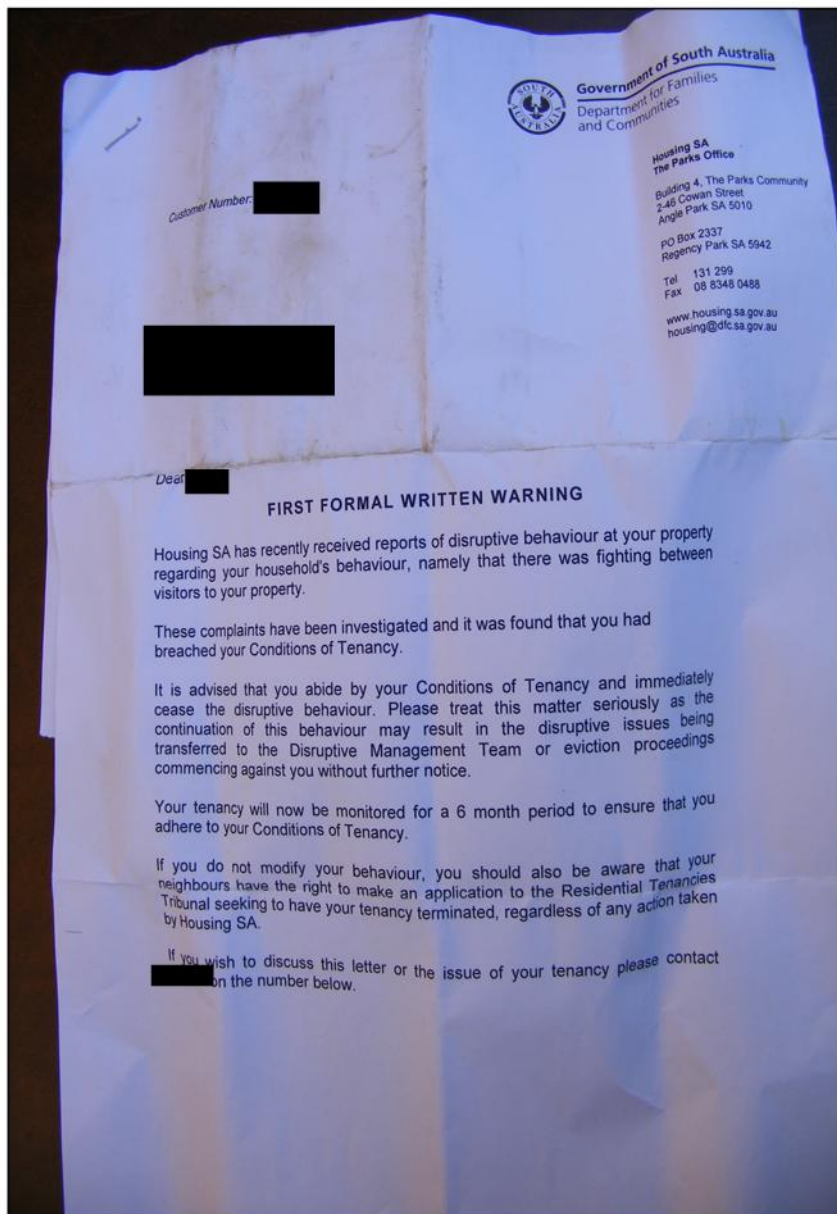


Appendix 1

Appendix 1



Appendix 2

Colin Brown



Hon Jenny Macklin MP

Minister for Families, Housing, Community Services and Indigenous Affairs
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600
jmacklin.mp@aph.gov.au

Dear Minister

My name is Colin Brown. I am an Anangu man from Ernabella in the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands in north-western South Australia. My wife, Yayimpi, is on dialysis, so we are living in Adelaide, a long way from our home country.

The nearest renal services to Ernabella are in Alice Springs. Alice Springs is about 450 kilometres from Ernabella, in the Northern Territory. 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 - although our people used to always go to Alice Springs for dialysis before. When Alice Springs first got dialysis machines and staff I believe that they would have been given them to provide services for Anangu people from the APY Lands. Now 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.

Alice Springs is too far from the APY Lands for our people to be able to live in their home country and travel for dialysis three times a week, but it is much closer to home than Adelaide which is about 1400 kilometres from Ernabella.

When my wife needed to go on dialysis this year we were told she could not be on dialysis in Alice Springs and had to go to Adelaide. She was told to go down to Adelaide by herself and stay at Luprina Hostel. We decided we wanted to stay together as a family and so with Yayimpi and my family, I drove down to Adelaide.

It was very hard. We had no house. We stayed at Amelia Campbell's place for a while. Yayimpi found going on dialysis was a hard thing for her. After a while with lots of people supporting us we did get a house. But it is hard. We can't just go back home and stay there if we feel sick of Adelaide, we have to stay here now. More of my family want to come and be with us.

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 they end up on dialysis.

Some people might be able to stay at Port Augusta where there is a renal unit but that is still a long way from home for Anangu.

There is also a big problem for Anangu who are on dialysis in Adelaide when a family member dies. They either have to stay in Adelaide and not be part of sorry business back in the APY Lands, or they have to rush up and back in three days. A day travelling up and a day travelling back doesn't leave much time to just be there. They used to be able to book in at Alice Springs for dialysis so their stay in the APY Lands could be extended. It seems they can't do that now.

I believe that the best thing would be for a renal unit to be located in the APY Lands, maybe at Umuwa or else at the old folks' home in Ernabella. I have some ideas about using the water from the dialysis unit for a vegetable garden or to grow fruit trees.

There seem to be more and more Anangu who are needing to go on dialysis. 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.

If we had a renal unit in the APY Lands it would help the Alice Springs and Adelaide hospitals because they would not have so many people needing their machines. Some Anangu who are living on dialysis in Adelaide and Alice Springs would be able to go home. This would free up not only dialysis machines but also houses and other services in those places.

I am asking for you to support my request for a dialysis unit in the APY Lands and to raise my request with the relevant people in Government.

Yours sincerely

Colin Brown
8th November 2009

Leonard Burton


Hon John Hill
Minister for Health
GPO Box 2555
Adelaide SA 5001
minister.health@health.sa.gov.au

Dear Minister

My name is Leonard Burton. My homeland is Wallany near Amata in the APY Lands.

I'm 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. I need help from you as the Minister for Health to help me and my Anangu people have a dialysis machine on the APY lands.

There are more Anangu getting kidney problems and they are going to have the same problem too and have to leave their homes and come to Adelaide. So I am writing to help these people too.

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.

I am a leader for my community up at Amata. I always talk really strong for Anangu tjuṯa. I am a member of the APY Executive, but it is hard to be so far away and to have to talk with the rest of the committee over a conference phone.

I am an elder for my Law. I have many responsibilities in my culture. I work hard for my people, for good things for them. 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 Lands and on dialysis it would be different.

We do things up there a different way. Down here it is hard for everything. We don't know how to live in the city, it is so different. I feel like government workers don't respect me and keep telling me I'm doing the wrong thing. Instead of getting to know me they seem like they just think I'm a problem. This makes me feel no good.

I think that this is how other Anangu feel too.

It is also hard being such a long way away from our bush tucker – you can't get good bush tucker down here. Our bush tucker is healthy food and makes you feel good when you eat it. I miss it.

I hope you can support us Anangu as we ask for a dialysis machine on the Lands.

I hope one day, when there is a dialysis machine available, I might be able to meet you up in the Lands.

Yours sincerely

Leonard Burton

February 2nd 2010

Yayimpi Brown



Hon John Hill
Minister for Health
GPO Box 2555
Adelaide SA 5001
minister.health@health.sa.gov.au

Dear Minister

My name is Yayimpi Brown. I am in Adelaide for dialysis. It is really, really hard in Adelaide.

I come from a community called Ernabella and I really want to go back there. It is my home up there, not here in Adelaide.

Also, in Adelaide it costs too much money for rent, electricity and water. We always have a problem with rubbish. We have a lot of rubbish and even though we use the wheelie bins it costs \$200 or \$300 for a skip to take the rubbish away all the time. HousingSA says that if we don't get rid of the rubbish in 14 days they will close our house. What happens to us then?

If they close our house where will I stay? I am on dialysis. I cannot go to Alice Springs any more. I cannot get dialysis in my home community. Where will I stay?

Do I sleep in a park or somewhere? Or go back to the community... but in our communities there is no dialysis - I would die. And I can't go back there because there is no house for us there anymore.

Sometimes I feel really worried and sad. I worry for going back up to my community. I want my family to be together up on the lands. Being on dialysis puts problems on me and my husband – I feel angry and we end up arguing and angry with each other.

I feel really tired and weak after four hours of dialysis. I don't feel good. I can't eat supper, or breakfast or lunch. I end up feeling really no good and really weak. I also worry about the kids at home while I'm on dialysis. I'm supposed to be looking after

them but I can't look after them while I'm on that machine. Something bad might happen to them and I should be looking after them.

Sometimes our family members pass away and we can't go up to the funeral. That's really hard. Maybe I could go up and spend one day and one night and come straight back to Adelaide but that is no good really, not proper way. We have no money to travel like that.

Also my kids don't like it down in Adelaide. They want to stay in the bush, in the community, not in the city. They don't like having to sit in Adelaide all the time because of me being on dialysis.

I have family who are down here in Adelaide drinking. They sometimes come and make trouble at our house. Nobody is looking after them down in Adelaide or up in the community. I'm their auntie, I wish I could take them back up to the Lands and look after them up there away from the drinking... but I'm sick.

It is the same story for many other Anangu on dialysis. Stuck down in Adelaide.

I am writing this letter because I am asking for help, for me and other sick people on dialysis. I want us to be able to have dialysis on the Lands. I want sick people from the Lands to be able to have the help they need on the Lands, and in Alice Springs, not just down here in Adelaide.

Yours sincerely

Yayimpi Brown

27 January 2010



Friday, March 12, 2010

MORE RENAL DIALYSIS FOR PATIENTS FROM THE APY LANDS

Health Minister John Hill has welcomed an in-principle agreement to secure renal dialysis in Alice Springs for kidney patients from the APY Lands.

“Health department officials from South Australia have reached an agreement with their counterparts in the Northern Territory and Western Australia to provide dialysis in Alice Springs for 8 permanent patients from SA and 6 from WA.” Minister Hill said.

“A re-elected Labor government will sign this agreement without delay.

“While this will have some impact, we know that we need more services to meet the escalating demand for dialysis for patients from the Lands.

“Plans are advanced for a new dialysis unit at Port Pirie with the capacity to treat up to 16 patients – this will free up capacity at Port Augusta for patients from the Lands.

“A re-elected Labor government will continue to expand dialysis services in South Australia – we have recently completed a \$1.8 million upgrade of the renal unit at Port Augusta Hospital and a new \$155,000 Renal Dialysis Unit at Whyalla Hospital.

“As well as these measures, we will look into the possibility of providing renal dialysis closer to the Lands, at Coober Pedy and – in the longer term – on the Lands too.

“Nganampa Health Council’s Medical Director, Dr Paul Torzillo, said “Nganampa Health Council is currently engaged in discussions with both the SA and NT Health Departments focussed on exploring closer to home dialysis options”.

Minister Hill said. “This process is in its very early stages and SA Health has made it clear the process will be completely guided by what Nganampa Health believes is the best approach, which I support.”

“The rapid rise in the number of people across central Australia who need dialysis has put pressure on the facilities in the Northern Territory and for some time now they have been unable to take new patients from South Australia.

“Since February 2009, four South Australian patients from central Australia have started dialysis in SA, one in Port Augusta, and three by choice in Adelaide.

“We currently pay more than one million dollars each year for dialysis for South Australians treated in the Northern Territory – a payment that also includes a component for capital and staffing costs.”

Appendix 6

Paper presented to meeting with key staff at Office of Minister for Housing (SA) on 24/7/2009
(slightly modified)

Support for Anangu living in Adelaide

At meetings of the Aboriginal Homelessness and Housing Support Branch associated with Shelter SA it has been emphasised time and again that for many Aboriginal families that getting a house is only step one and that it is crucial appropriate supports are put around the newly housed person or family.

In many respects with Anangu coming to Adelaide I believe the model needs to be like a new arrivals program for refugees. While some Anangu have a significant (and some even a problematic) history with Housing SA there are still significant parallels to newly arrived refugees:

- They are people in exile from their own land and homes
- They have arrived with almost nothing
- They have little or no history of positive connection into the mainstream community and economy
- There are significant language and culture differences
- There are few established "Anangu-friendly" or "Anangu-managed" organisations or services in place down here.
- There is often an attitude among Aboriginal organisations and workers that "Anangu are too different", or a threat, or shouldn't be down here when they have their land and resources being poured in back up there

I believe there needs to be an organisation or approach that is adequately and appropriately resourced and staffed that is pro-active and works with Anangu householders who move down here to try to identify options and assist them to make a more successful transition into the community down here in Adelaide. There are a range of issues and practical questions that such a person or organisation would need to address:

1. Options for or assistance with acquiring furniture and household goods and necessities.
*Usually Anangu have little or none of even the basics.
I believe there are baseline needs that should be addressed whether through charity donations, Centrepay arrangements, NILS loans or appropriate credit arrangements.*
2. Options for or assistance with moving any furniture and household goods and necessities they can acquire into the residence and setting up. *Many Anangu have no car or trailer.*
3. In winter – adequate heating and blankets etc In summer adequate cooling if needed.
I believe there are baseline needs that should be addressed whether through charity donations, Centrepay arrangements, NILS loans or appropriate credit arrangements.
4. Solid pro-active financial management plan – identify pre-existing debts and fines that need addressing, plus lock in financial arrangements for covering future rent, power, water, chemist and ambulance costs. Ensure Centrelink arrangements are in place and working.

Need to draw in and gain commitment of all income earners. May need initially fortnightly follow up to track how its working and deal with glitches.

5. Identify any addiction and issues that might impact on finance management plan and household stability. *I believe there is a great need for far improved Adelaide-based Anangu-friendly addiction services.*
6. Identify any health and mental health issues that may be impacting individuals, the family and the neighbourhood.
I believe there is a great need for far improved Adelaide-based Anangu-friendly health and mental health services.
7. Develop a workable plan for yard maintenance and garbage removal
(Most Anangu households have big issues with rubbish. I believe that a skip up to 6 times a year may be needed).
8. Develop rapid response plan to address any internal housekeeping and maintenance issues early, and gardening and outdoor maintenance.
I believe a participative approach is best
9. Develop rapid response security plan to address any issues with drunken relatives etc. Tenancy holders need to meet and get to know some local police. The "Return to Country" program within Safe Tracks (or something like it), needs to be able to swing into action as close to any crisis as possible, while tenants have strong feelings and are willing to insist people should go – otherwise things calm down and normalise and the tenant feels obliged to keep the perpetrator there while the perpetrator becomes distant from any feeling of guilt which might encourage going back to their own home and emphasises the tenant's obligations.
10. Establish close support of Anangu with high level health needs as they become settled into dialysis – concerns over the instability of housing arrangements so far can cause worry and fea. Some Anangu have expressed a feeling of being weak and powerless (and losing hope) in the transition into dialysis.
11. Try to connect the whole family into broader mainstream health support programs – and whatever is left of the Mud Hut program.
12. Older kids can go to Wiltja but the other kids need to connect successfully into a school. Mansfield Park PS has been the most obviously effective school for Anangu kids as far as I'm aware – would they pick up from the relevant area?
13. Kids need school uniforms, shoes etc to feel they have best chance of fitting in.
14. Any health issues with going to school need addressing
15. What opportunities for adults in the house to find some kind of work or positive community involvement (maybe X has good English/Pitjantjatjara skills – is there potential? Maybe a painter – what about Better World Arts?)

I've made up this list just reflecting on my previous experiences with Anangu down here in Adelaide. It is my perspective and if you talk with Anangu there may be some things I've listed which they don't agree with or other things they think are very important. It is certainly not a comprehensive list. Nevertheless, I believe Anangu tenancies are going to be at extreme risk of failure unless there is a proactive approach along these lines adopted. I believe the approach needs to be one of seeing the arrival of Anangu in Adelaide as a positive opportunity not an insurmountable problem.

Anangu need someone who will work alongside them at their pace, not rush ahead and do it for them, or turn against them if they take a while to get in tune with life in Adelaide.

It seems glaringly obvious that such an approach needs an organisational structure, adequate resourcing, and appropriate staffing. At one stage I had hoped the Safe Tracks proposals might be a way of progressing this. I'm now unclear about who is going to pick this up and run with it. I would be keen to talk further about what is happening in this area if anyone wants to follow that up with me.

Last updated Dean Whittaker December 7th 2009

GOVT FAILING TO PROVIDE ADEQUATE HEALTH CARE FOR INDIGENOUS PEOPLE IN REMOTE SA

The Uniting Church SA is calling on the government to provide better access to dialysis for people living with chronic health issues in the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands.

A resolution passed at this weekend's meeting of the SA Synod of the Uniting Church calls on the State and Federal Governments to:

- Remove the barriers that currently prevent critically-ill people from South Australia's APY Lands from accessing renal dialysis in Alice Springs.
- Investigate the pros and cons – and comparative costs – of providing renal dialysis in a range of settings, including in remote Aboriginal communities like the APY lands.

In early 2009, the Northern Territory Government decided that it would no longer let people from the APY Lands relocate to Alice Springs for renal dialysis.

This decision has forced a number of South Australian Anangu patients to leave their homelands.

“Driving from the APY lands to Adelaide is like driving from Adelaide to Sydney for treatment. Obviously, you can't do that every three days. Relocation is the only option. To uproot people from their families and separate them from their homelands is cruel,” says Rev Rod Dyson, Moderator of the Uniting Church.

The Uniting Church believes the pressure on the health system will continue to grow. Between 2003 and 2007, the number of Indigenous Australians on dialysis climbed from 772 to 1066.

Last December, the Western Australian Government agreed to negotiate a new arrangement with the NT Government so that WA renal patients living east of Warburton could, once again, access dialysis services in the Northern Territory.

So far the South Australian Government has been unable or unwilling to negotiate a new cross-border arrangement with the Northern Territory Government.

Close to 300 Synod members unanimously voted in support of the Uniting Church's call on the government for a more humane approach.

Further background information is available on the Uniting Care Wesley Adelaide's Paper Tracker website:

http://www.papertracker.com.au/index.php?option=com_content&task=view&id=214&Itemid=57

Rev Rod Dyson, Moderator of the Uniting Church, and Rev Peter MacDonald, Minister, UnitingCare Wesley Adelaide, are available for comment.

Rev McDonald co-presented the proposal to the Synod and visited the APY lands last month to