



Dialysis in Central Australia

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Current Issues in Indigenous Affairs

U3A Hawthorn

On a recent visit to Alice Springs I visited a small renal dialysis centre run by a Western Desert Co-op with a very long and unpronounceable name. It is near to the huge Renal Dialysis unit run by the Hospital, the largest in the southern hemisphere.

Many people in Alice Springs and the surrounding country suffer from kidney failure and without dialysis they would die.

There is a widely held misconception amongst white people that renal failure is due to alcohol abuse, but the reality is that there are many other contributory factors. Poor food, poverty, low birth rate, diabetes and heart problems amongst aboriginal communities are all factors in its growth.

The Co-op I visited is run by a board made up of indigenous people from many of the Western Desert communities. The administrative centre is in the Purple House, in Flynn Drive, Alice Springs, in a very unpretentious weatherboard house, surrounded by a quiet, beautiful bush garden.



The Purple House

The Purple House, where I was taken on my arrival, was alive with activity.

There are four Dialysis chairs (as they are called) in the house and they operate daily. Clients have 3 sessions a week with 5 hours each time. After treatment they sit around, eating, chatting, and filling in the time. A number of the women I met had been on dialysis for 5 to 8 years and have to live in, or around, Alice Springs in town camps or with friends. They seldom get back to their own homes and are far away from family, friends and country. The feeling of dislocation is profound.

The aim of the Co-op is to raise money for dialysis machines in all of the community centres, so keeping people in their home surroundings. "Taking our people back home" is the motto of the Co-op.

Some twelve years ago this Co-op was kick started by an amazing auction of aboriginal art in Sydney. I quote from the summary report of the Co-op November 2006:

"On the evening of 11th November 2000 at the Art Gallery of NSW in Sydney, social commentators Rampaging Roy Slaven and H.G.Nelson compered an extraordinary auction of Aboriginal art works in collaboration with Sotheby's Australia. Inspired by indigenous dissatisfaction with mainstream health services, the intention was to raise money to enable Yanangu - people from the cross-border Western Desert region of Central Australia, affected by severe kidney disease to return home on dialysis, rather than have to move permanently to Alice Springs for treatment.

Auction night was a huge success. Australian and international collectors had donated thirty one original works of art by Australian indigenous artists, alongside a further four specially commissioned collaborative paintings done by senior Pintupi men and women from Walungurru (Kintore) and Kiwirrkurra. Just over \$1 million was generated from their sale to global bidders, including \$300,000 paid by Kerry Stokes for the Kiwirrkurra Mens' painting.

The money was used to fund the development and subsequent activities of Western Desert Nganampa Walytju Palyantjaku Tjutaku or WDNWPT (literally 'Making all our families well'), an organisation representing those Yanangu families on dialysis."

While I was in Alice I stayed at a house leased by the Co-op and used by nurses and other workers coming in to Alice after long stints out country. During my stay, there was a New Zealand couple there who had been at Kintore for 2 years and were going back to N.Z for holidays but then returning to their work in the desert. The wife was a very experienced renal nurse and her husband found himself very useful doing jobs on the community and picking up and delivering anything you might name.

The other person in the house was a young paramedic who had been volunteering on a community for 3 weeks, was returning to Melbourne, but planning to go back to the community to do further community work. Meeting these people gave me a great opportunity to learn about their work and to hear their opinions on current policies.

During my visit I went out to Hermannsburg, the nearest community to Alice Springs. It was the first Aboriginal Mission in the Northern Territory, and was established by the Lutheran Church in 1877 on the traditional lands of the Western Aranda people. It is Albert Namatjira's country and Hermannsburg is well known through his paintings.



I had learnt about the work of the Aboriginal Co-op while in Darwin in 2010 during the Festival when I went to a play called 'Head full of love', written by

Alana Valentine and directed by Wesley Enoch, an aboriginal man, and performed by aboriginal actors. This play was based on the stories of the aboriginal women who were undergoing dialysis as they made beanies. The Beanie Festival which grew from this is now an annual event in Alice and attracts participants from around the world.

Reading the programme afterwards I saw it was supported by The Purple House in Alice, and the name of the Co-op was given. It was suggested that anyone interested in their work could ring the number in Alice for more information.

This I did and spoke to a woman called Sarah Brown. She subsequently sent me a twenty one page report outlining the backgrounds of the Co-op, a very impressive document which caught my interest.

In 2011 Sarah Brown was in Melbourne talking at a dialysis conference and I met her. She told me if I wanted to visit some time I would be welcome. Sarah started as manager of the Purple House five years ago and before that she had had 15 years of experience as a rural nurse. It turns out she must be the best person for a very demanding job. She has the ability to raise funds, an ongoing part of her job. Sarah drives the project in a quiet, but very forceful way. She is now the CEO.

Recently the opportunity for me to visit Alice Springs arose.

At Hermannsburg, some 200 km South West of Alice, the Purple House operates a two chair renal unit. At 6.15 am I was picked up in Alice by Rita, the renal nurse going out for the day. We drove for one and half hours through the orange ranges of the West Macdonalds. Rita had years of experience as a rural nurse, but then decided she wanted to specialize in dialysis so did the one year post graduate training necessary to become a dialysis nurse. She loves her work.

I had previously visited Hermannsburg in 2002, and at that time it impressed me as an interesting historic precinct and well looked after. This time it seemed rather run down, lots of dogs in packs wandering round, the church yard full of weeds, gravestones of early settlers covered over, many people just wandering aimlessly, or watching the ubiquitous film crew making yet another film.



Hermannsburg

I spent the morning in the 30 degree C corrugated iron renal unit where 2 patients, Edna and Arnold were having their 5 hour treatments. Edna was quiet and reserved, Arnold a big, talkative man. He spoke 4 languages, Walpiri, Pitjanjaru, Aranda and English.

My first job was to make breakfast, not an easy task in a very tiny space, with a microwave and a sink. Scrambled eggs turned out like a heavy four inch high cake, but the tinned beans and beef accompanying it moistened it a bit. This was followed by slices of toast with marmalade. I was given the thumbs up for my cooking.

Arnold watched TV for most of the time, but I realised as I cooked I was being intently watched by Edna, a small woman, with a beanie low to her eyes, one of which looked blind, wrapped up in rugs as she waited for the needles to go in and her breakfast. At one time I spun around as I heard the signature tune for the French TV programme Miniscule. Arnold was entranced for a short time.

It all felt like a dream, and somewhat incongruous.

By 9.30 am the dialysis was in full swing . It was hot and quite noisy, the beep-beep of the machines unrelenting. Rita could not leave the unit at all during the day, as amongst other things she was constantly monitoring the machines to check if the patients' blood pressure was stable.

After some hours I went out and explored the area. A children's centre was alongside the renal unit, and a flourishing garden surrounded it. Kolrabi was everywhere, a good source of green vegetable but the aboriginal women did not like it or pick it. Pitcherry, the native tobacco abounded. The women grind this up and mix it with ash to form a chewable paste which produces a pleasing and sedative effect.

I walked around the dusty little town, a bit wary of the dogs of all shapes and sizes, sizing me up. A visit to the store horrified me. The price of all fresh food ~~was~~ exorbitant; a cabbage cost \$10. Income management cards were in use; the owners not allowed to have grog or cigarettes, but many of them leaving with coke and chippies.

I felt angry about it, but was told the managers of these community stores are responsible for getting the goods out from Alice and can charge what they think they can get away with. There is no government subsidy.

Next to the store was the famous Hermannsburg pottery, where six women were at work hand modelling and then painting their iconic pots. Many of these potters now sell round the world and their work is in all our major galleries. I was told that Bill Clinton owns one of the Chook Chook pots.

I am no expert on dialysis, but in a short time I learnt a lot about it. As one of the workers from Kintore said to me, "Dialysis is a growth industry". And from what we hear and read here it is growing rapidly too in our society.

Many of the patients out bush are diagnosed with renal failure, end stage kidney disease, very late and their only real option is to go on dialysis if they wish to stay alive.

Simply put, renal dialysis is a medical process of filtering the blood with a machine outside the body, to rid the body of harmful wastes, extra salts and water.



A dialysis chair in use

The patient has 2 tubes inserted into the veins of the arms, and a flow of blood is pumped from a vein, treated to prevent clotting and passed over a membrane surface, on the other side of which is a sterile solution containing the concentration of salts of healthy blood. The red and white blood cells are too large to pass through the pores of the membrane but the excess salts, urea and other contaminants (poisons) can do so. The blood is then returned to the patient. This is a slow process and needs repeated circulation.

The nurse on duty monitors the tubes for 5 hours, checking the flow and the blood pressure which might have soared up to 210. The fluid removal brings it down.

In the Northern Territory all the machines used are German Fresenius machines, and are leased from the company. The contracts may be 5 years then renewed when new machines become available. In the contract Fresenius technicians do the maintenance. Some contracts include dialysis chairs and dialysis lines. Sometimes the chairs are purchased.

The approximate cost per person for this treatment is between \$80,000 to around \$96,000 per year. In Australia the government pays through the health system. This treatment is the only option for indigenous Australians. Kidney transplants are not an option. There is a three year wait for them, due to the low level of organ donations.

When I returned to the unit Rita asked me to take Edna back to her home. Feeling rather daunted driving a big car over the sandy roads, we made the trip to her simple corrugated home, a big three-and-a-half legged dog waiting outside to greet us.

Edna got slowly out of the car, and went to sit outside her front door on a broken chair.

As we walked she looked at me, and said, "How old are you?". I told her and, rather taken aback, I said "How old are you?". She thought for a moment and said, "I think -- maybe, maybe 73" to which I responded, "Well then, I'm boss". She laughed her head off. It was a lovely sound.

As I drove off, I looked back. The sun was beginning to set, the nearby hills purpling and the chill of the desert night setting in.

I had been told that Edna had two sons in Hermannsburg. But that they seldom visited her. She had come home from this dialysis treatment with food to help her until the next treatment, two days off. Like our *Meals on Wheels*, a lunch box is given to old and sick people by the Department of Health, together with a dosette box of pills.

As I looked, she was opening her food box and I felt sure she was going to share the contents with her scraggy dog -- my last and memorable sight of her.

Reflecting on this visit after my return I had very mixed feelings about what I had learnt and observed, but it was overall an inspiring story of aboriginal self-determination driven by Western Desert people to get appropriate treatment and it is undoubtedly a success story.



The Purple Truck – a mobile dialysis unit

*'It's more than
machines and medicine:
they should understand,
there's a Yarrangu Way'*



WDNWPT Summary Report 2006

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