Scoping Study for Lajamanu Dialysis Project

August 2010

Invisible Disease – Silent Voices

Figure 1 Lajamanu

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Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation WDNWPT

Supported by the Kurra Aboriginal Corporation

Executive Summary and Recommendations to Kurra Aboriginal Corporation:

Imagine leaving your home and family with a one-way ticket and no prospects to return! Lajamanu is 890km from Darwin and currently, there is little chance to get home once you are on dialysis.

Through wide ranging interviews we established there are strong community and health arguments for a dialysis program at Lajamanu to enable Lajamanu and Kalkaringi people on dialysis to reconnect with family, community and country and to develop new approaches to reducing the harm caused by kidney disease.

Some key steps and decisions are required by the community in order to proceed on this path

- Governance systems - community, financial & clinical
- The type of dialysis to commence
- The funding strategy

Governance systems:

The Kurra Aboriginal Corporation has, for several years, shown leadership in developing opportunities for dialysis at Lajamanu. Kurra has an important function in supporting projects but is not designed to manage a project. As a step in developing a local, governing committee, we asked people if they wished to play a role on a Kidney Committee. We were overwhelmed by interest in taking on this leadership role. The committee features cultural leaders from both Lajamanu and Kalkaringi and many years experience governing other organisations including local government, health services and the Kurra Committee.

Kidney Committee

Helen Nungarrayi Morris – Chair
Jerry Jangala Patrick
Doris Nakamarra Lewis
Robert Japaljarri George
Joyce Napaljarri Nakamarra Herbert
Roger Japaljarri Jurrah
Steven Jampijinpa Patrick
Geoffrey Jungarrayi Barnes
Geoffrey Jakamarra Matthews
Valda Nungala Naparulla Kelly
Kathleen Nampijinpa Duncan

For the project to succeed the governing committee will need to take a strong role in advocating for dialysis at Lajamanu and meeting regularly to ensure the project stays on track.

We recommend the Kurra Committee support the Kidney Committee to formalise its governance through meetings and forming a new Aboriginal corporation with a goal of ensuring a local dialysis program.

The project requires partnership with an existing organisation with a record of managing funds and employing staff in order to begin attracting support. It also needs to work with an organisation with clinical governance experience and a record of working with very sick people. Dialysis is a very technical procedure requiring specialist staff.

Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT) has the skills and structures needed to auspice this project. It has developed a service level agreement with the Northern Territory Government to access machines and water treatment equipment and shared care of dialysis patients. One challenge is that medical services direct patients to Darwin and Katherine from this region and WDNWPT are based in Alice Springs. After talking the potential challenges through with a variety of people including Sarah Brown, Manager at WDNWPT we conclude WDNWPT is the best option.

Sarah Brown, Manager, WDNWPT met with Helen Morris, Chair, Lajamanu Kidney Committee in August 2010 and said WDNWPT would be happy to establish an auspice arrangement.

We recommend WDNWPT auspice the Lajamanu Dialysis Project for a minimum of 24 months.

Choosing a dialysis model

In the report we describe the ways that some Aboriginal people with renal failure have made it back to their home community – transplantation, Self-Care peritoneal dialysis and Self-Care haemodialysis. However, these ways have got very few people home to Lajamanu and Kalkaringi.

We recommend Lajamanu and Kalkaringi, through the Kidney Committee, develop a Nurse Assisted Haemodialysis, Return to Country Project at Lajamanu.

This model would enable HD recipients from Lajamanu and Kalkaringi access to HD in Lajamanu for periods of 2-6 weeks several times per year in order for them to maintain family, country and cultural connections. A nurse with two machines can give 14 people the opportunity to have three, one month visits to country each year.

We suggest the project establish its own premises, accommodation and vehicles. Thus, while working closely with other organisations - shire council, clinic, progress association, land council etc. it would have operational independence. Negotiating suitable land tenure with the Land Trust, Federal Government and the shire council will be a key early step.

This project is a similar size to that started in Yuendumu in 2010. However, the remoteness of Lajamanu creates some additional costs for construction and transport.

The funding strategy - money story

The plan is presented, as three stages to be completed in turn and that could be completed over the next three years.

Stage 1. Employ Manager. To;

a) Seek new funds for next Stages.
b) Commence building dialysis centre.

Budget: $574,000

Stage 2. Nurse Assisted Dialysis. Addressing the pressing need to start getting dialysis recipients back on country with their families. It involves transport to and from Darwin and Katherine for nurse assisted dialysis visits several times per year.

Budget: $815,000

Stage 3. Holistic Kidney Health Service. We need to take extra care for people when they are dialysing both in towns and in home communities, especially as they get old. Also, in the home communities we need to teach all the community about caring for their kidneys so that fewer people get problems and those that do can spend longer at home before starting dialysis

Budget: $977,000

Once Stage 1 is fully underway with construction initiated and the Kidney Committee and the manager focused on the task, we suggest funds can be successfully sought for Stage 2 and Stage 3 from a range of sources including the Federal Government, Tanami royalty funds, community grants and philanthropic sources.

We recommend the Kurra Committee support Stage 1 of the plan through funding in the 2010-11 year of $574,000. This will put the project in a position to commence dialysis in the second half of 2011.

As a second option, Kurra could part-fund Stage 1 through salary support for a manager whose task would be to commence applying for all funds required and to cover governance work. This would be a minimum of $90,000 in 2010-11. This level of funding would result in a much slower path to commencing dialysis.

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Background to Study:

Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) Aboriginal Corporation is a not for profit, community based organisation providing town-based and remote dialysis services. Initially the service was for Western Desert Dialysis patients. The success of the project has enabled other communities a way forward in returning to country while on dialysis. The existence of the WDNWPT Kintore and Alice Springs renal facilities is well known to dialysis patients and their families across Central Australia.

Kurra Aboriginal Corporation agreed in early 2007, to set aside $30,000 for the Central Land Council to appoint a consultant to conduct a feasibility study for the provision of dialysis support services for Warlpiri patients from Lajamanu, Yuendumu and surrounding Warlpiri communities. WDNWPT was appointed to carry out the study drawing on its relevant expertise and experience. As of Friday, 6th August 2010, the Yuendumu Renal service is operational. However, self care training, social support and return to country activities have been operational in Alice Springs for several years.

Recently, WDNWPT also assisted Ntaria to set up an in-community dialysis service.

In 2007 Jeff Hulcombe conducted a feasibility study in Lajamanu finding overwhelming good will and enthusiasm from community members and community organisations alike for the establishment of social support and dialysis service. There was also support from a range of organisations in Lajamanu, Katherine and Darwin.

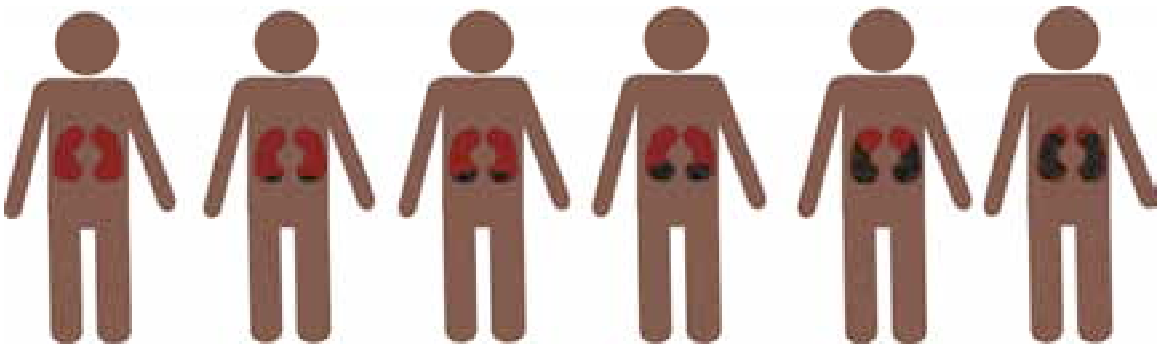
From WDNWPT's experience, the fundamentals for a successful project at Lajamanu appeared to be in place. Most significant is community enthusiasm and engagement.

There was however a number of critical issues yet to be resolved. These include;

- Who would auspice the project?
- What other external funding or other forms of assistance could be available to assist this project eg. Central Desert Shire, the Commonwealth Government, Katherine Western Health Board (KWHB), Department of Health and Families
- What would be the catchment area for clients?
- How could patient support and return to country programs be instigated which addresses the dispersed nature of clients accessing dialysis services in Katherine and Darwin.

- How self care may be promoted and best incorporated into the service.
- Location of the facility.
- Matters of staff recruitment and accommodation.
- Whether a governing committee is required and if so how will it be established? Is a separate incorporation desired or required?

These questions led to more money being put forward from the Kurra committee, to further investigate and resolve the above issues. Consultants were employed through WDNWPT to commence a scoping study. In June 2010 the Scoping study began.



Methodology and Acknowledgements

The Lajamanu Scoping Study is primarily a qualitative analysis of the feasibility of having dialysis in Lajamanu. The parameters in which we worked were laid out by the brief from the Kurra Committee and followed the 2007 study conducted by Jeff Hulcombe from WDNWPT in 2007. We also reviewed literature from various renal researchers, providers and funders before we set off to talk with people.

Figure 2 David describing different renal models at Darwin meeting

Our meetings followed a path similar to the Mother Trail (Davis-Floyd 1992; Sweet 2010) - opportunistic meetings alongside meetings that had been organised. We consulted a variety of respondents including community family members, government bodies, renal patients from both Kalkaringi and Lajamanu based in Katherine and Darwin, researchers, renal nurses, social workers, medical practitioners as well as attending a renal conference. For some of the meetings we went in with particular questions regarding fields of expertise while other

interviews conducted had an open framework allowing for the core issues to be revealed without pre-emptive questions.
The variety and breadth of people we interviewed has enabled this study a depth of investigation in a relatively short period and enabled us to investigate many aspects of the renal story.
Despite being primarily qualitative, we have also analysed some quantitative data expressing the numbers of people on dialysis, eGFR values etc.

Figure 3 Meeting with Darwin renal mob and families

Graphical representations of dialysis were enabled by Reddirt Graphics, Alice Springs. For help in translating the legends to the graphics we thank Helen Morris and Lauren Campbell (Gurindji) and Bess Price (Warlpiri).

Numerous people gave freely of their time and we are very appreciative.

History of Lajamanu and Surrounds:

Figure 4 Katherine West Region
From the KWHB website.

Lajamanu

Based on 2006 census, Lajamanu has a population of 790 people and is situated half way between Darwin and Alice Springs in the Northern Territory. Lajamanu is 557 km from Katherine and 890km from Darwin. Katherine is the nearest town with a sealed road except 100km. Despite people originally being from Central Australia, the Top End services this community. Heavy rains can in the wet season cause creeks to rise, cutting off the Buntine Highway, Lajamanu's north-eastern access road. Kalkaringi is situated 101 km from Lajamanu on a dirt road.

Lajamanu was settled as a response to what was perceived as over crowding at Yuendumu.

Being taken away from country, family and sacred places made people unhappy, so they walked 600km 'home' – back to Yuendumu. The sense of displacement and dislocation still goes on today as dialysis patients leave home to go to Darwin to stay alive on a machine.

By the 1970's a relationship had formed between the Gurindji people at Wave Hill and the Warlpiri living at Hooker Creek. Ceremonies took place where the Gurindji people handed over some country and Dreaming to the Warlpiri settlers.

At this time local government was formed and Lajamanu formed the first Community Government Council in the Northern Territory.

Katherine West Health Board (KWHB) was established in 1998 with the help of Helen Morris the chair of the Lajamanu dialysis kidney committee. KWHB is the auspicing entity for the clinics at both Lajamanu and Kalkaringi.

On 1st July 2008 the Central Desert Shire was established which took over from the Lajamanu Community Government Council along with many other community organizations now controlled by the shire. Assets were transferred at this time and the staff was given the option to now work for the shires. Many people are still trying to understand the role of the shire. Norbert Patrick is the president of the Central Desert Shire and a Lajamanu man.

Figure 5 Norbert Patrick with Brogas Tjapanardi (seated) at the Purple House June 2010.

Both Lajamanu and Kalkaringi with Dagaragu are named Growth Towns in the NT and Lajamanu is a Remote Service Delivery (RSD) site allowing Federal as well as Territory input directed to improving infrastructure as well as economic and service delivery for the communities. A Local Implementation Plan (LIP) is being developed for Lajamanu involving the government departments and the people at Lajamanu. The LIP is supposed to look at the needs of the community, what will work, what needs to be fixed. The budget includes seven areas to be revised and added to: Early childhood, schooling, economic development, healthy homes, governance and leadership, health, safe communities.

Kalkaringi: 'From little things, big things grow'

Kalkaringi and Dagaragu are about 8 kilometres apart and connected by a sealed road, and are therefore often placed in the same basket for service providers. In 2009 a $4 million clinic was built to service both these communities with a joint population of 750-800 people.

Figure 6 The renal ready room at the Kalkaringi clinic

Renal Disease and Remote Aboriginal People

For Aboriginal people from remote settings with renal failure the foreign environment of the hospital coupled with being away from family, country and ritual practices which have sustained peoples wellbeing has a traumatic effect, and people often describe depressive states, crave going out bush and returning to their country and kin.

Visits home to sites remote from dialysis centres do occur but often require people missing dialysis sessions and becoming sick - sometimes to the point of requiring air evacuation. Anecdotal evidence along with research of Devitt and McMasters (1998) suggests people are willing to wear the health risks of missing dialysis as long as they have been able to return to country for some period.

> "Their health is further adversely affected when extended community visits mean poor dialysis attendance. The consequence of this is an increase in acute admissions and greater severity of co-morbidities (Gorham 2003, p.18)"

Dislocation from land also includes elders who have a central function in their communities. An elder being moved off country disrupts the passing of important knowledge. Through informal activities such as hunting, bush medicine/ tucker collection, sitting around cooking kangaroo tail, the community begins to hear the stories and understand important practices. When someone prominent leaves due to illness, the whole community misses out on important obligations and responsibilities being 'passed on.'

> "[J.L describes extensive travels on law business before getting sick] His inability to now attend is not only a personal loss for him, but an enormous loss for the whole community, most particularly those young people whom he would, under normal circumstances, be instructing (Devitt & McMasters 1998, p.53)"

There is a growing body of research highlighting the importance of reconnecting to law, ritual, family and country for a sense of health and wellbeing (Atkinson 2001; Carson et. al 2007; De Ishtar 2005; Devitt & McMasters 1998; Grieves 2009; Rivalland 2006; Sweet 2010; Trudgen 2000).

> "Prominent and influential men and women who disappear from community and community affairs to undergo medical treatment are felt as a loss in a personal sense to their relatives, but it is also a serious issue for local community life (Devitt & McMasters 1998, p.53)"

Emerging research illustrates the importance spirituality places on recovery, the ability to cope and wellbeing for people living with illness. For many Aboriginal people, Spirituality is closely linked to country and family (Atkinson 2001; Bell 1998; De Ishtar 2005). There are many accounts of the spirit becoming sick when you're away from home. 'Looking' for family, the spirit searching for family and connection to family and country. People worry for their family and cultural obligations which can restrict their ability to feel better (Nayutah & Finlay 1988).

> "Any assessment of the true cost of providing dialysis services for people from remote areas in the urban setting must also consider its impact on the community. People who have to move away from their community and family have a greater need for support services. Costs incurred by the community include increased burden on priority housing, more disability pensions and lack of employment opportunities for spouses (Gorham 2003, p.17)"

An economic impact study for renal disease in Australia (Cass 2006) suggests end stage renal failure will increase in the tune of 19-47% of people requiring renal assistance per annum.

The impact for families and particularly children of renal families is evident.

> "The significant number of unpaid debts due to the increased cost of living in urban setting impacts on the social workers and Aboriginal Liaison Officers, involving the Aboriginal Legal Aid service, interpreters and court time. Moreover, schools must provide language and other support for the children of people on dialysis. Children who feel the lack of friends, familiar faces and languages may be more inclined to be truants and as a result their numeracy and literacy levels are likely to decline (Gorham 2003, p.17)"

Economic impact studies are important to demonstrate the numbers of renal patients and the monetary costs this places on us as an Australian population. An economic impact study for renal disease in Australia (Cass 2006) suggests end stage renal failure will increase in the tune of 19-47% of people requiring renal assistance per annum.

There is scarce literature linking the economic and social, emotional impacts of dialysis recipients (Devitt & McMasters 1998). Gill Gorham (2003) indicates there are several issues which need considering for renal patients. Lack of suitable housing in new cities and towns is a concern for most renal clients and their families. Dislocation has an impact on many aspects of community and personal life. For example, the need for extra finances for travel costs; flights, petrol and maintenance of cars to get family home, rental costs for patients and supporting and visiting family (Gorham 2003).

> "Such sadness [of being away from family] is no transient emotional state, it is a deep, existential loneliness in which the possibilities of social life-normal life-are almost extinguished (Devitt & McMasters 1998, p.49)"

Devitt then goes on to comment on the essential nature of kin

> "It [family relations] is perhaps the single most significant determinant of a patient's ability firstly, to cope with and, then, to persevere with their treatments (Devitt & McMasters 1998, p.50)"

As patients are removed from their country a sense of loss not only for community but also their 'job' or place is lost. Returning home allows this knowledge and pride to return.

Activities, which give a feeling of connectedness and familiarity, facilitate wellbeing on a deeper level.

> "It is probable that the capacity for hope, empathy, a sense of connectedness and respectful communication with loved ones are essential ingredients in the 'control factor', a recognized psychosocial variable in epidemiological patterns of disease. Increased control and mastery means that people have greater capacity to deal with day-to-day challenges of life without being overwhelmed by them (McEwan & Tsey 2009, p.2)"

Figure 7 Helen Morris, proposed chair of committee on dialysis in Katherine

The Self-Care model of dialysis enables someone to take responsibility for his or her own health, reduces the inconvenience of travel to a dialysis centre and is cost effective. In Australia in 2008, of the 10,062 people on dialysis, 22% of the total were on home peritoneal dialysis and 9% home haemodialysis (Australia and New Zealand Dialysis and Transplant Registry, 2009). However, when considering Indigenous patients, the percentage able to take advantage of these Self Care modalities is only 13% (158 of 1147) and 5% (55 of 1147) indicating there are barriers for Indigenous people going down this path. Of relevance is that access to Self Care training is only provided to those meeting stringent personal and health criteria and requires confidence in dealing with calculations and many new terms. After being trained, patients need to have access to housing, a trained support person and a suitably secure site for their equipment. After returning home they need to maintain, find and arrange housing. Due to educational and social disadvantage many Indigenous people have difficulty satisfying all of these criteria. Similarly, Indigenous people receive one third fewer kidney transplants than the rest of the population (McDonald, 2004).

In 1976 the first home dialysis treatment was offered in the Northern Territory and in 1980 the first home dialysis training unit opened in Darwin. By 1983 the unit was relocated to Nightcliff so that it may service more clients. Despite self-dialysis being the preferred option most Indigenous people are unable to access this service, as they are considered 'unstable'. Medical stability is considered to be those patients who can maintain their blood pressure and pulse rates at optimal levels while they are on a haemodialysis machine (Noble 1996). Due to a variety of reasons, such as inability to control fluid intake, cardiac function and, on occasion, missed dialysis sessions most Indigenous dialysis recipients are considered medically unstable.

In 2007, Australia's Chief Medical Officer shed light on the challenge of delivering renal dialysis services in Central Australia: "Patient numbers threaten to overwhelm the capacity of the staff and facilities to deliver services, and there is a need to have these services much closer to the communities (Horvath 2007, p.13)".

In 2003 a document titled 'Prevention and Treatment Options for Renal Disease in the Northern Territory' (Gorham 2003) was published. This report examined many issues for renal patients particularly Aboriginal people in the Barkly region.

An economic analysis concludes that "interstate and overseas costings generally agree that, if transplantation is not possible, the next most cost-effective option is home dialysis followed by peritoneal dialysis and satellite haemodialysis (Gorham 2003, p.41)."

Gorham (2003) makes some interesting observations based on literature reviews. She notes that the cost for hospital haemodialysis is the most expensive and that expenditure increases with delays to treatment or confounding co-morbidities; such as heart disease, diabetes and anaemia. Another general recognition was that treatment and prescription for renal disease clients needed to be individual, this may "involve expensive treatments in return for long term benefits such as quality of life, decreased admissions and length of stays (Gorham 2003, p. 42)"

> "Most countries were now considering incentives to encourage people towards home therapies, recognising that people on home dialysis had a better survival and quality of life than people receiving in – centre or at a satellite unit (Gorham 2003, p.42)"

In the Northern Territory there are two major renal centres, Darwin and Alice Springs hospitals, with satellite units set up in Tennant Creek, Flynn Drive (Alice Springs), Nightcliff (Darwin), Palmerston (Darwin), Katherine, Tiwi (Bathurst Island), as well as a new private centre opened in 2010 in Alice Springs. Unfortunately, despite the growing number of dialysis machines, people are often still a long way from home and have very little chance to get back to country.

As other reports state (Devitt & McMasters 1998; Gorham 2003), there is no simple solution to the escalating renal disease in remote Northern Territory, and as such a broad review needs to be done to understand and potentially advocate for new and alternate models of care for renal patients, their families and communities, keeping in mind the needs of the people directly affected and perhaps adopting a 'patient centred care plan'.

The recently initiated 'Central Australian Renal Study'[1] will hopefully highlight the issues, challenges and positive outcomes for all the current models of care for dialysis patients in the Northern Territory. Recommendations from the study will have an impact on what will be funded in the future.

Figure 8 Exterior of Nightcliff Renal Unit, one of the NT satellite renal centres

Findings:

Below are the key findings. For details of the consultation process and outcomes please see Appendix 1.

High Rates of Dialysis and Kidney Disease

There are high rates of kidney disease at Lajamanu and Kalkaringi. Partly this is because kidney disease is a silent disease. Many people do not know they have damaged kidneys. If they get a check up and the clinic tells them their kidneys are not working well, they will be asked to take different medicines that keep their blood pressure down, to be careful with their diet and to learn about the disease. Because it is a quiet disease people often do not feel better if they listen to this advice. So some people do not listen. Some people may be scared to think about their kidneys failing because then they will have to go to Darwin and live there.

The distribution of those on dialysis away from community is presented in Table 1 and shows the 13 people are split 7 and 6 between Lajamanu and Kalkaringi. This data is similar to other studies in showing a greater number of females than males on dialysis.

Table 1 Origin, location, type of dialysis and gender for dialysis recipients from Lajamanu and Kalkaringi.

	Males	Females
Darwin PD	Nil	1 (Kalkaringi)
Darwin HD	1 (Lajamanu) 1 (Kalkaringi)	3 (Lajamanu) 1 (Kalkaringi)
Katherine PD	Nil	1 (Kalkaringi)
Katherine HD	3 (Lajamanu)	1 (Kalkaringi)
Kalkaringi PD		1 (Kalkaringi)

(PD, peritoneal dialysis, HD haemodialysis. Data from meeting family and dialysis recipients and cross checking with each on location of people from the same community.)

The national rate of people requiring dialysis is 471 people per million (Australia and New Zealand Dialysis and Transplant Registry, 2009). The rate for the Northern Territory is more than three fold any state at 1810 ppm. Based on the 13 dialysis recipients currently alive (excluding one fatality during the study) and populations for Lajamanu and Kalkaringi of 790 and 800, the rate for this region is 6840 ppm. This region is suffering a disproportionate disease load.

There is one lady residing in Kalkaringi using PD and another lady in training. From our enquiries, there are no other dialysis recipients on the wait lists for Self-care training. There appears to be no interest in PD from Lajamanu dialysis recipients and we understand this is related to the death in recent years of a Lajamanu person who had a 'bag'.

Table 2 Patients with identified Stages 3, 4 and 5 kidney disease for community members at Lajamanu and Kalkaringi.

	Lajamanu	Kalkaringi
eGFR < 15 (stage 5)	7	3
eGFR 15-30 (stage 4)	nil	1
eGFR 30-60 (stage 3)	29	17

(Data courtesy of KWHB, Jul 2010).

Table 2 shows that currently, within the communities, there are many people approaching end stage renal failure. The majority of these 57 people will experience renal failure and have the options of passing away or commencing dialysis. Depending on their choices, there is a potential for a significant increase in demand for dialysis over the next 1-3 years. Unidentified cases of renal disease may also be significant.

Everyone we spoke to had stories of family members who had died or not returned home since going on dialysis. Darwin seemed far away for most people and there was even a story of a Lajamanu man's sister who went to Perth, when first on dialysis then made her way to Broome. She has been away for several years. Unfortunately for her and her family she passed away within the period of this study commencing.

Dialysis Creates Disconnection From Country and Family

Figure 9 Painting by Helen Morris depicting people leaving community to go on dialysis.

In talking with 8 dialysis recipients from the region in Darwin and Katherine, all said they had no opportunity to return home, and that their families could not easily visit due to financial and health constraints. One way for a dialysis recipient to get home is travel by road while limiting their fluid intake. Due to the long distances from Darwin and Katherine to Lajamanu and Kalkaringi and limited funds and accommodation this trip is rarely attempted.

One lady in Darwin described missing 6 funerals while being on dialysis, which made her sad.

“I’ve missed 6 funerals since being here, they don’t let me go, one’s coming up for my nephew in Hall’s Creek” (dialysis recipient in Darwin)

The interviews in the study confirm the findings from numerous studies on the impact of institutional dialysis on people from other remote Aboriginal communities in Australia. The responses we gained outlined the traumatic effects both on the renal patients and their community. Some are in Appendix 1. For example;

“We just want to go back and be with family” dialysis recipient in Katherine.

[Referring to people with 'kidneys starting to fail']
'A real worry for the community" Community member.

"We really want to bring our families back" Lajamanu man not on dialysis

"We want [a] dialysis machine here" Woman in Lajamanu not on dialysis

Two themes that were highlighted by respondents were firstly, senior community members are not able to take part in important decision making meetings, hand on important knowledge and take their place in family life. Secondly, we were told that the next group of people whose kidneys are failing are neither presenting to the clinic for treatment of their condition nor learning about the disease and the treatment options. This denial of their condition has adverse health outcomes, probably decreases the time they may remain at home before dialysis and creates a situation where they enter dialysis in crisis.

Strong Community Support for Return to Country

All community members we spoke with were very familiar with dialysis and had personal experience of its impact through loss of a close relative. They all declared dialysis back on country as a high priority.

"We all talk about this, dialysis here" Woman in Lajamanu not on dialysis.

"I am happy to be on this committee, I've been talking [about] this one, we want this here, those machines, what's that name" wife says "Dialysis" "Yes that one, a man came here in a hat and spoke Luritja (Jeff Hulcombe) and we thought it was a good one, we want that, I been thinking we need that. Our family go away sick and no good when they worry for kids, grandkids and family, they may go looking for their family and get sicker." Senior Lajamanu man living on community.

"It's important to come back to family and country when you are finished." Senior Lajamanu man living on community.

There was also strong dialysis recipient support for return to country. All beside one woman on dialysis was keen to have visits back home.

Initially we were told one Lajamanu lady had no interest to return, however, when we met with a renal nurse, she indicated this woman did not want to live back home but was keen to go back for visits.

“If they do put machines in Lajamanu we can go in the morning and come back, its not far” she said “we just want to go back and be with family, that mob at home should be supporting us, keep talking with them [people about getting machines home]” Kalkaringi dialysis patient.

“They need dialysis there [Lajamanu]” Lajamanu dialysis client in Darwin.

“Family don’t visit us here, too far, too much money.” Lajamanu dialysis recipient.

“We miss family” Lajamanu dialysis patient.

Figure 10 Lily Jurrah at home in Lajamanu

Lajamanu and Kalkaringi Share Dialysis Facility

Given Kalkaringi (with its sister town of Dagaragu) is 100 kms from Lajamanu; the potential for including this community in the project was obvious. Lajamanu community members had no hesitation in endorsing this idea and from its initial formation the Kidney Committee has featured representatives from both localities and both nations, Warlpiri and Gurindji.

"We can have it at Lajamanu and Kalkaringi people come there." Kalkaringi dialysis (PD) client.

Figure 11 Lajamanu with clinic in background

Kidney Committee

The kidney committee was formed by community consultation. Initially in Lajamanu we talked to people about what we were doing and who wanted to be involved. Many people were keen to be involved and a number of these people self nominated or were nominated by other community members to go on the committee. Unfortunately the day the first meeting was to commence the weather changed and dispersed people as the rain and cold set in. The community members who did come to the meeting although disappointed in the turn out noted it did not reflect the importance the community placed on having a dialysis machine back home. We experienced overwhelming

positivity about the project. Even an hour leading up to the meeting many people were gathering at the meeting site.

The committee members reside in Darwin, Katherine and Lajamanu and represent both communities, both nations, dialysis recipients and their families.

Helen Nungarrayi Morris – Proposed Chair
Jerry Jangala Patrick
Doris Nakamarra Lewis
Robert Japaljarri George
Joyce Napaljarri Nakamarra Herbert
Roger Japaljarri Jurrah
Steven Jampijinpa Patrick
Geoffrey Jungarrayi Barnes
Geoffrey Jakamarra Matthews
Valda Nungala Naparulla Kelly
Kathleen Nampijinpa Duncan

Figure 12 Jerry Jangala Patrick - committee member, Beth Barnes and Michelle at their home –Lajamanu.

Figure 13 Doris Nakamarra Lewis at Lajamanu – committee member

Helen Morris the chair of the committee came to Alice Springs on 6-7th August to contribute to the report, to learn more about the Purple House and to meet directors and staff. She and most members of the committee will gather in Lajamanu, August 24th to put their position to the broader community.

Types of Dialysis Available in the NT and Ways to Get Home

In order to compile considerable information the following graphics were prepared to illustrate the processes and alternatives in commencing dialysis, living on dialysis in major centres and potential paths home. While it necessitates much simplification, we hope it provides a basis for greater clarity.

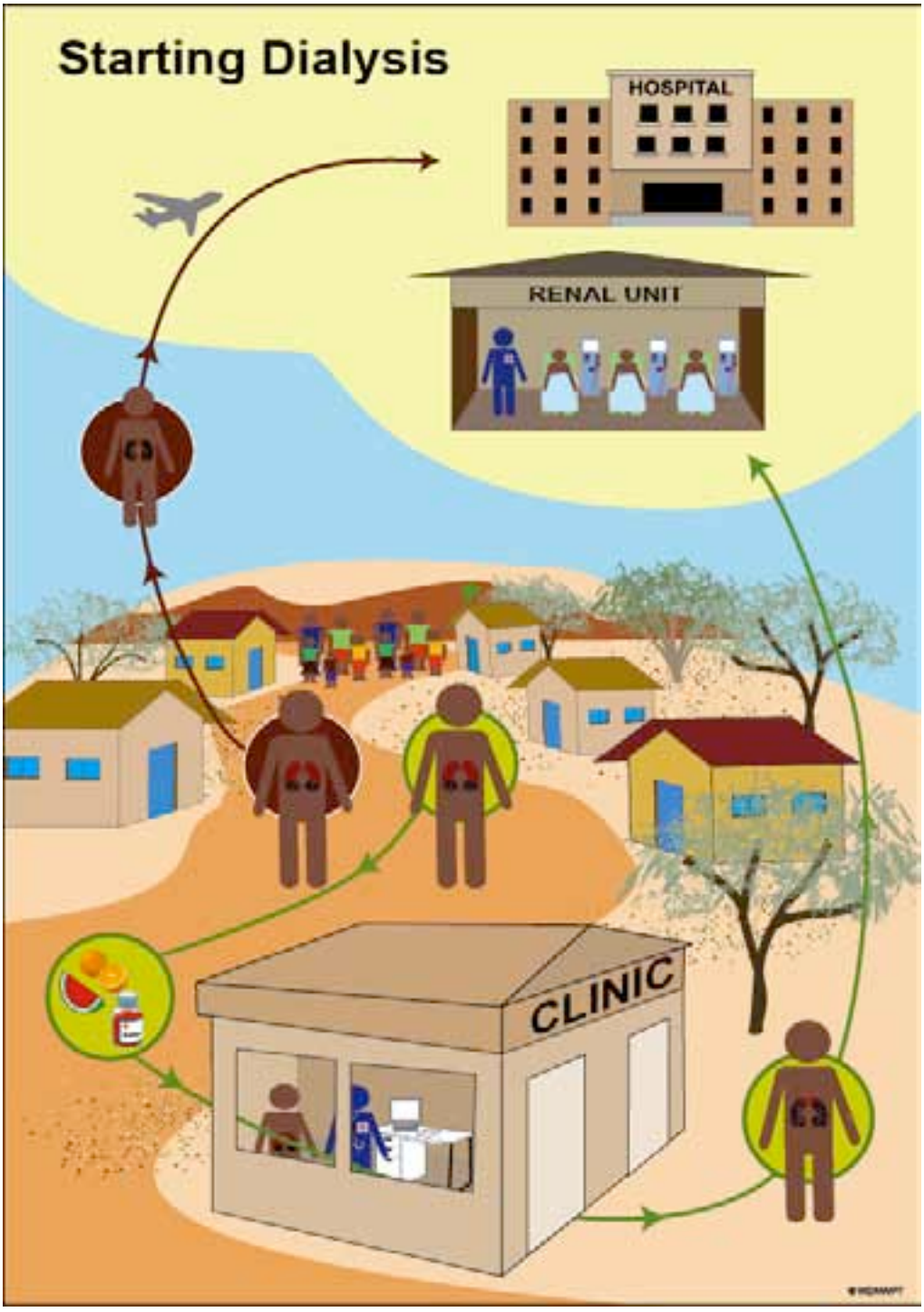


Figure 14 Starting Dialysis

English
Starting Dialysis
There are two different paths onto dialysis. Quick and slow. For some people the path is quick because they do not know they have a kidney problem or do not listen to the clinic that they have a problem. They feel OK but their kidneys get worse quickly. They find out they have kidney problems when they start to feel really sick and they have to go to hospital. Sometimes they are so sick a plane flies them there. In the slow path the person gets a check

up and finds out there kidneys might fail one day. They decide they want to stay home as long as they can. To do this, they listen to the clinic to learn about protecting their kidneys, they are careful about what they eat and they take medicines. Before the kidneys get too bad the nurse may suggest they get a fistula put in their arm. This takes time to heal up. Taking care of their kidneys people can live for many years at home. Some might never have to leave.

Warlpiri
Dialysis-ki ngarnti
Jirrama ka karrimi dialysis kirrajarrinjakuju. Kapanku marda manu pulya marda. Yapaju ka kidney maju jarrimi kapanku yangka kuja ka nyinami purda nyanjawangu, clinic wangu manulpa miyinyanja wangu marda nyinaja. Yapa kidney maju, ngurrju marda kanpa nyanu purdanyanyi, ngula karraju kidney nyuntu nyangu ka majujarrinjani. Purdanyanyi kalu nyanu nyurnu wirilki. Ngulajangkaju yanilki kalu hospital-kirra. Pintapintarlu ka jana kanyi, nyurnu wirilki. Yapaju kalujana ngarrirni yangka nyanungurra nyangu kidney kapu nguwu-jarrimi pulya. Ngurrangka kaji ka nyinami. Kujaju clinic-kirra yani ka, purdanyanjaku. Yungu nyanu nyarrpangku warrawarra kanyi, nyiya ngarninjaku manu nyiyapiya medicine. Kidney ngurrjungkarni kapulu nyarra wangkami yirraninjaku fistula, ngulaju kalu yirrarni wakungka. Kajinpa nyanu jungangku warrawarra kanyi kidney nyuntu nyangu kapunpa taarngka ngurrju nyinami.

Gurindji
Nyila-ma ngu kujarra difren way dialysis-ku, waja-wu an yamak-ku. Nyila waja-wu ngumpin-ku nyamu kula ngarrka manana nyila kidney problem o kula kurru nyangana clinic-ku. Maidi nyila nyamu filim manana punyu nyanuny kidney. Yalanginyi nyila nyamu karrwarnana problem, wankaj karrinyana waja. Nyila-ma yanku waja ojpil-jirri dialysis-ku. O nyila samtaim nyamu karrinyana janga nyamu filim manana rili janga, nyila-ma yanana ojpil-jirri aeroplane-ta. An nyila nyamu yamak, nyila nyamu yamak karrinyana nyila ngumpin manana check-up an yangki panana nyanuny kidney-wu. O nyamu yanana wankaj, nyila-ma karrinyana ngurra-ngka-rni ngajik nyamu-nga kurru nyangana clinic-kula kurruwaran an ngu pinak karrinyana. Ngu-nyunu karrwarnana punyu punyuk nyanuny kidney-ma an nyila-ma-nyunu warrawarra nyangana. Nyamu jartkarra nyangana tanku an medijin nyamu kangana bifo nyanuny kidney get tu janga prabli wankaj. Nyila-ma nurse-ma nyila ngu-nga-rla marlu ngu karrwawu 'fistula' nyanuny wartan-ta an yalanginyi-ma i ken warrawarra mijelp nyanuny-ma kidney-ma ngumpin-tu-ma. Yalanginyi-ma karru-nga nyila-ma ngajik-piya ngurra-ngka-rni.

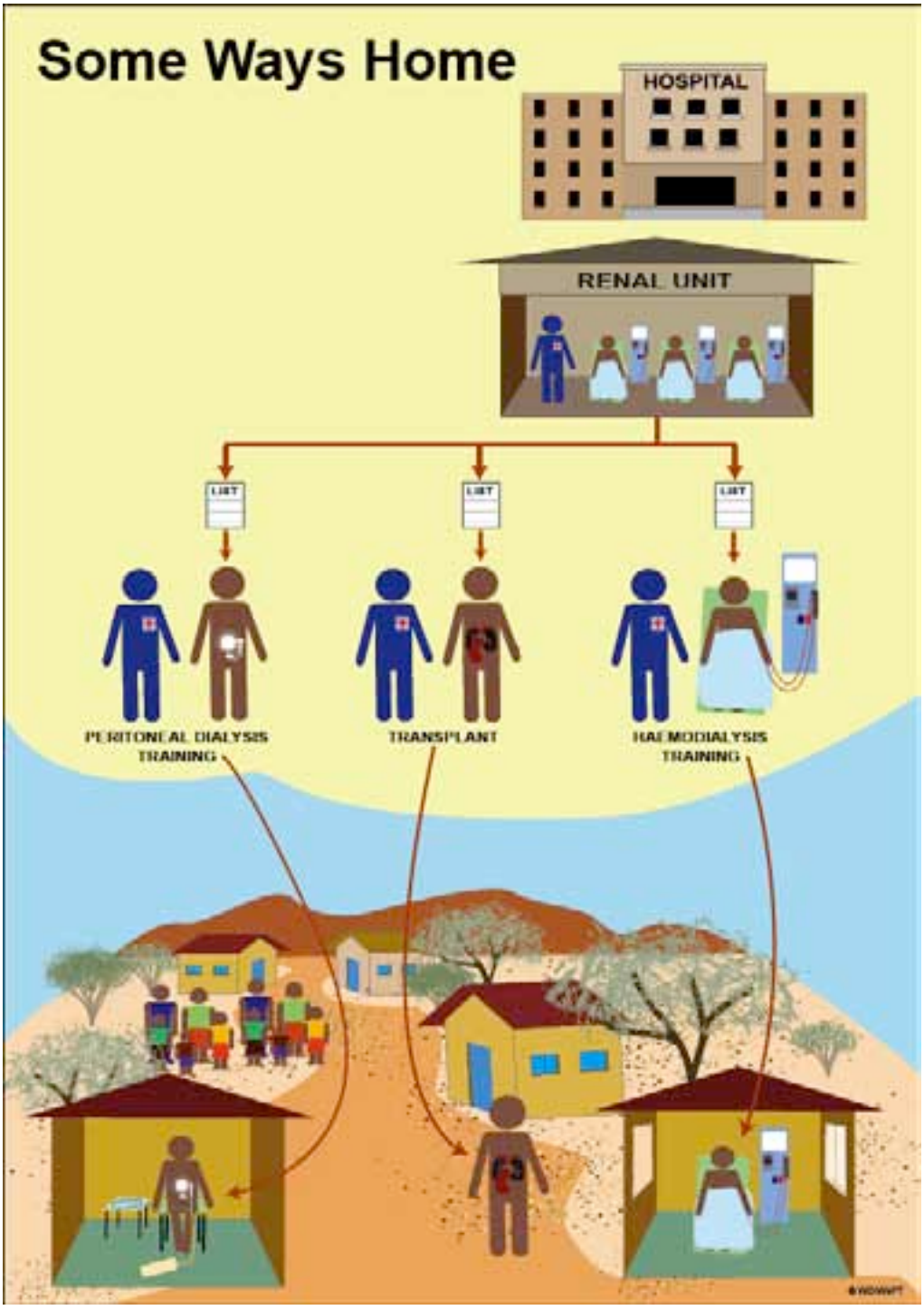


Figure 15 Some Ways Home

English
Some Ways Home
Some community people get home by getting a transplant, getting trained in peritoneal dialysis (with the bag) or haemodialysis (with the machine). Doing any of these is hard and scary. You have to learn many new things and keep everything clean. It can be hard to get on the list for any of these ways home and you need to be healthy. Only some people get home these ways.

Warlpiri
Ngurra kurraku
Yapa panu kariji pina ngurra kurrajarri kalu transplant jangka manu peritoneal dialysis,kirli manu marda haemodialysis kirli. Transplant ngulaju yangka yinjawarnu kidney yapa warlalja kurlangu marda manu marda jintakari kirlangu. Peritoneal dialysis ngulaju miyalurla kurlu bag pardu. Ngula kurlulu kanpa nyanu kirlka mani. Haemodialysis ngulaju machine.Kajinpa nyampurra kurra jarrimi, ngulaju kapulu nyarra yijardurlu pinapina yirrarni nyarrpamaninjaku. Yangka nyarrpangku warrawarra kanjaku. Nyampuku ngarntiji ngurrju nyinanjaku.

Gurindji
Nyawa-ma nyamu nyila ngumpin wart yanana nyanuny community-ngkurra ngajik-parni, tumaji karrwarnana new-one kidney. Nyila-ma nyamu-rla manana 'transplant'. Nyila PD-yawung. Wi gedim training nyila-ma bo 'P.D.' Dialysis bag nyila-ma-lu tarl panana, nyamu-rla manana majul-ta. Nyila-ma mijelp-parningan ngu-rla doem manana ngurra-ngka. An nyila-ma nyuntu yu garra learn an nyila-ma ngun-nyunu karrwa kilka, kipim nyununy abrijing kilka, ngurra-nganyju. An nyila ‘haemodialysis’ nyamu-lu kolim marnana nyila-ma 'machine'. Machine-ta nyamu-rla karrinyana. An nyuntu yu garra learn an kipim nyununy abrijing kilka. An nyila nyamu-rla doem manana machine im bit wukarra-wukarra tu, yu wukarra.

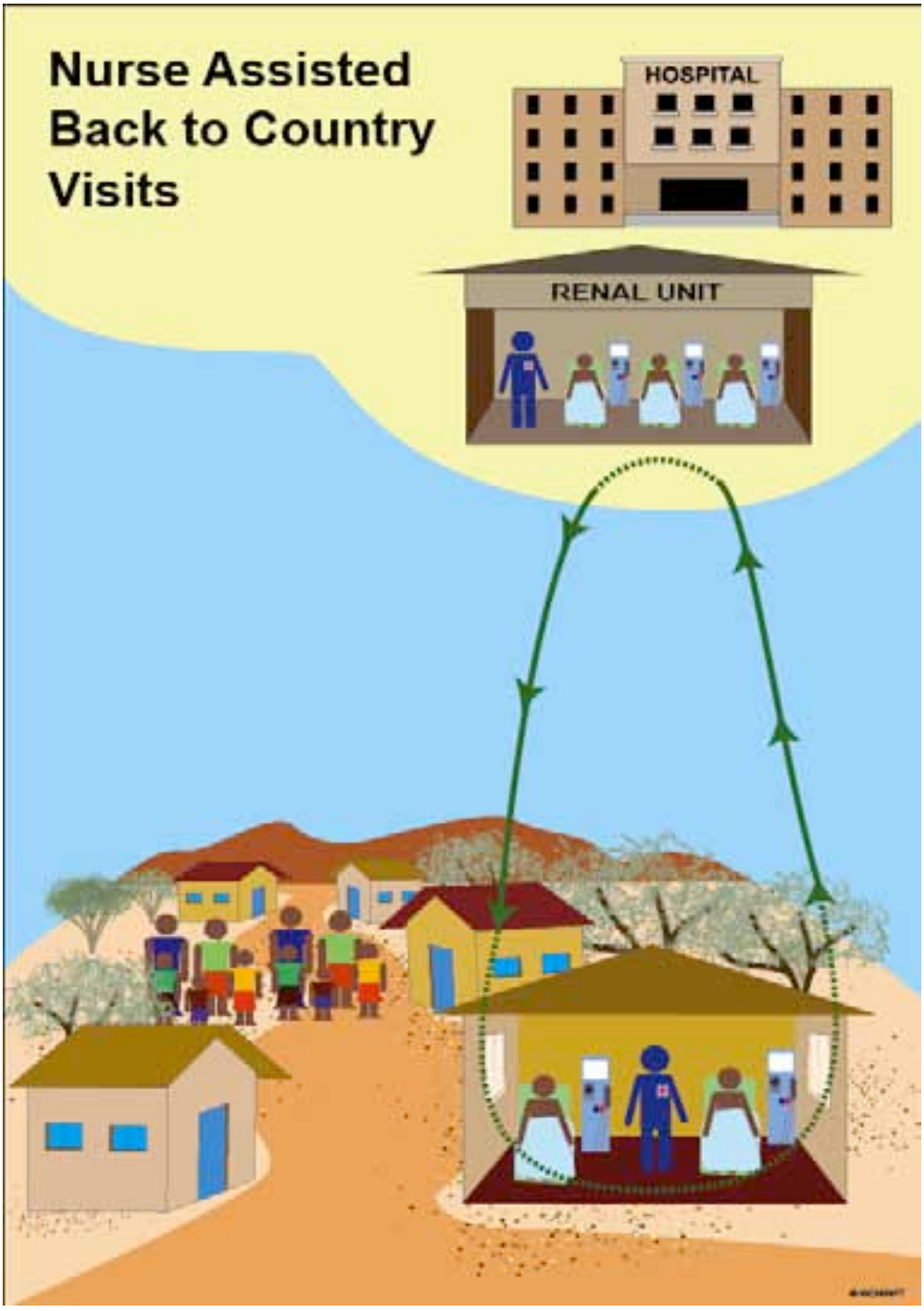


Figure 16 Nurse Assisted Dialysis

English
Nurse Assisted Dialysis
People on dialysis return to country and family for weeks at a time and have a nurse to assist them. They leave and someone else comes for a visit.

Warlpiri
Dialysis nguru walarljarla jijakurlu.
Yapa dialysis wardingki kaji kankurlu pina yani yapa walarlja kurra. Palka kapu nyarra jija nyinami, warrawarra kanjaku. Ngulajangkaju kapunpa jana panu karikilki yampimirra.

Gurindji
Nyila-ma ngumpin-ku nyumu-rla dialysis-ta, yanku ngurra-ngkurra, yanku wart community-ngkurra country-ngkurra nyila-ma family-wu. Nyila-ma nyamu-rnalu-nga manku nurse-purrupurru nyantipany-ku ngurra-wu. Nyila-ma only fo kapla week, kula karru ngajik-parni, ngaju-nga karru jintaku jakiliny. Nyila-ma nurse ngu-ngatipa patient-ku waruk karru community-ngka an abimbat dialysis nyila-ngka-rni. Yalanginyi-ma nyila-ma-rnalu wart yanku igin maiti town-jirri-rningan maiti Kajerrain-jirri o Darwin-jirri.

Table 3 Care provided to NT renal failure patients in 2008.

	Renal Centre	HD Self Care	PD Self Care	Transplant	Total
All Recipients	346	20	32	74	472
Aboriginal	325	16	23	36	400
% Of Aboriginal	81%	4%	6%	9%	100%
Non-Indigenous	21	4	9	38	72
% of Non-Indig.	29%	6%	13%	53%	100%

Data from Australia and New Zealand Dialysis and Transplant Registry (2009).

Following consultations with NT, Department of Health Family staff involved in the HD Self Care, PD Self Care and Transplant programs the data on the numbers of Territorians receiving renal therapy from December, 2008 (Table 3) appears to reflect the current picture in 2010.

One exception may be a trend in the number of Aboriginal transplant recipients decreasing due to attrition. Following peak numbers of transplants in 2004-2006 (9, 4 and 7 transplants in each year respectively), the number in the year 2008 (1 transplant) appears to reflect the current rate. The two transplant renal nurses in the NT we

spoke with identified the poor availability of live donors related to the recipient who had healthy kidneys as the major barrier for Aboriginal transplantations.

Considering relatively few Aboriginal people call the major centres of Darwin, Katherine, Tennant Creek and Alice Springs home, opportunities to live at home are very limited. For Aboriginal people, 83% of the renal service population are confined to major centres while the non-Indigenous population has only 29% restricted in where they choose to live.

Selecting a dialysis model for Lajamanu

Our comments on each type of dialysis are:

Peritoneal Dialysis (PD)

Two Kalkaringi people are actively engaged in learning or doing PD. However, following a fatality perceived as being linked to 'the bag' in Lajamanu, no community members are following this path and it may not be accepted at Lajamanu in the near future, if at all. We talked to several Aboriginal people with PD experience and excellent health knowledge who found PD impractical too hard. Also, while PD is an effective early treatment, subsequently another treatment (usually HD) is required. While this method deserves support, this options is not recommended to start the project:

Self-Care Haemo Dialysis

While many Lajamanu and Kalkaringi HD patients have seen this mode, none have chosen to undertake training. In the Territory, the proportion of dialysis recipients who have achieved Self-Care status is less than 5%. Once a person has success in Self-Care, when they get older, eventually they will find the process too difficult and unable to undertake dialysis without assistance. While a viable option for some, this method will be applicable to very few current and future people from this area.

Self-Care guidelines are strict about ensuring patients remain focussed on their self-care practise. Fortunately, the clinic at Kalkaringi has a room identified solely for Self Care, as does the next clinic to be built at Lajamanu. Therefore, when some people are trained for Self-Care,

space will be available. The project will support them wherever possible. Procurement of stores and disposal of biohazard waste are areas of common interest.

Nurse Assisted HD, Full Time Unit

A haemodialysis unit with all recipients living and dialysing full time in Lajamanu would be the choice of some people. However, we spoke to some current HD patients who would prefer to keep their accommodation in Darwin and Katherine while making visits to country. Also, to provide equitable access to all people wishing to live in community e.g. 8+ people on HD, such a unit would require a large infrastructure and staffing requirement that is currently beyond realistic funding.

Nurse Assisted HD, Return to Country

This model would enable all HD recipients from Lajamanu and Kalkaringi access to HD in Lajamanu for periods of 2-6 weeks several times per year in order for them to maintain family, country and cultural connections. Enabling these connections is the focus of the responses to our consultations and this is the only model that will achieve this within a reasonable time frame. We recommend this model.

We suggest the project establish its own premises, accommodation and vehicles. Thus, while working closely with other organisations - shire council, clinic, progress association, land council etc. it would have operational independence. Negotiating suitable land tenure with the Land Trust, Federal Government and the shire council will be a key early step.

Potential Auspicing Organisations

Who Can Hold the Money and Employ the Staff for a Dialysis Service?

A number of different options were explored in this study.

Lajamanu Progress Association

A local community owned entity that operates two enterprises, Lajamanu Air and the Lajamanu Store. The CEO said the organisation was unable to take on an additional function.

Katherine West Health Board Aboriginal Corporation

Is a regional health service with clinics at Lajamanu, Kalkaringi and five other communities with headquarters in Katherine. Staff indicated they would take this report and its recommendations to their next board meeting.

A New Entity

Advantages of a new community controlled organisation would be that it could maintain a locality and culturally appropriate service. In Yuendumu, their Kidney Committee is currently forming Tanami Regional Dialysis - Ngalipaku Walalja Ngurrjumaninjaku Panuku Aboriginal Corporation. This organisation is currently not employing any staff, but rather having WDNWPT auspice the service. The aim is that, eventually the local organisation will be in a position to govern all of the Yuendumu dialysis program. Similarly, Lajamanu and Kalkaringi may form an organisation with similar goals. Given the community has also identified aged care as a priority area for future funding and that primary healthcare and governments are having difficulty delivering services to old people in remote sites effectively, a local Aboriginal corporation could be started to govern a combined aged care and dialysis unit. The authors are putting this option in the report.

Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT)

Advantages of WDNWPT taking on this role are its experience in managing, funding and operating similar services in remote sites. Their experience working with both Aboriginal and Government culture is valuable. WDNWPT already have service agreement in place with the NTG and have a number of renal nurses waiting for positions in communities. The corporation's directors have been consulted about their willingness to direct resources away from their focus in the Western Desert, and are supportive of auspicing the Lajamanu project. Recently, they have been prepared to support auspicing for Ntaria and Yuendumu. An option is for WDNWPT to get the Lajamanu service on a secure funding and operational level and then transfer management to another organisation.

Funding Opportunities

Federal Government

Department of Health and Ageing (OATSIH) are the most obvious source of support. They have supported proposals similar to the one recommended here in Kintore, Ntaria and Yuendumu. Our advice from them is that they need very clear local support and look favourably on proposals that have additional funding sources.

Other Federal departments may be willing to support different aspects of the project. FaHCSIA for governance and leadership development, DEET for training of community staff for health and support staff.

Remote Service Delivery (RSD) Communities/Growth Towns

Lajamanu is on both lists. Kalkaringi is identified as a Growth Town. While this Federal and Territory initiative is only starting to find its feet, the concept of providing hub towns with a range of services relevant to the region is aligned with this proposal. In order to gain support, the community must be mindful of keeping dialysis facilities and funding part of all planning.

Tanami Royalty Funds

Kurra Aboriginal Corporation, Granites Mine Affected Area Aboriginal Corporation and individual mining companies have supported a range of project. For example, GMAAAC have supported Western Desert Dialysis to start some return to country flights in 2010 for dialysis recipients coming to Lajamanu for 2 days without dialysing. In the past they have supported: Warlpiri Youth Development AC (Mt Theo), PAW

(Pintupi, Anmatyerre, Warlpiri) Media, WYN (Willowra, Yuendumu, Nyirrpi) Health AC, Lajamanu Clinic, Yuendumu Old Peoples, Yuendumu Mining Company, Wulaign Outstation Resource Centre, Lajamanu Air, Yuendumu Social Club Store, Central Desert Shire (Lajamanu oval resurfacing), Warnayaka Art Centre, Alpirakina Store.

Community Grants

Potential grants rounds include Aboriginals Benefit Account, Aboriginals Benefit Foundation, and Community Benefit Fund (NTG), Rio Tinto Aboriginal Fund etc.

Philanthropy

Western Desert Dialysis has shown how philanthropic donations can be very important for bringing in money and allowing the Australian community to show how much they want to support Aboriginal people living within their cultures. They have got funding from individuals (as art purchases and as a donation), pharmaceutical companies, dialysis companies and medical societies.

The project addresses a big problem for the communities - losing people with a lot of skills and knowledge. Again, the key for success is a strong local committee with the community behind them.

We suggest starting to write proposals to a broad range of potential funders - a 'leave no stone unturned' strategy.

Social Support in Katherine

Helen Morris as a long time health worker , health sector leader and a dialysis recipient made a clear case for the need for a Katherine facility to provide support for Aboriginal people from across the region on dialysis. Such a centre could provide social and cultural activities such as short respite trips for picnics, bush medicine or bush tucker collecting, campfires as well as support transport and accommodation needs. DHF staff also indicated social support was required and, given significant expansion of the Katherine service, with eight new chairs announced in the 2010 NT Budget, this need will increase. While Helen envisages this service operating from a dedicated 'house', we suggest initial funding requests could be for staff to commence support activities - a 'virtual purple house'.

Renal Therapy is Not Primary Health Care

Primary Health Care is the focus of remote health services - General Practitioners and generalist nurses acting as the primary point of contact for a range of illnesses. Treating people with renal failure has not been considered a part of Primary Health Care. To some looking in – community members, government staff etc. they express surprise that dialysis services are not accommodated by remote clinics. However, Primary Health Care staff are not trained in the complex and life threatening states of renal failure or dialysis and will not take responsibility for these types of patients.

In order to spend time in the bush a renal therapy recipient must first be stable. Once in a remote setting they require a clear point of first contact to get specialist advice and support. For Self-Care patients, they have a nurse in Darwin or Alice Springs who is familiar with them and their circumstances. In the WDNWPT system that renal nurse is with them in community.

In recent years, remote clinics are being constructed with 'Renal Ready Rooms'. These rooms have additional power and water outlets for haemodialysis machines and an external door. The external door provides access to Self-Care patients enabling them to dialyse without calling on any clinic staff. In the event of a question or a mishap, their first point of contact is their Self-Care coordinator in the city

Compliance as a Problem

Compliance was a term, which was mentioned regularly when discussing renal options. Compliance in medicine refers to the patient conforming to the recommendations/guidelines/rules established by the medical authorities. Lack of compliance was a recurring theme throughout the study. Examples include renal disease patients in remote communities who were not taking medicine to postpone disease progression or accepting a fistula as preparation for dialysis. Once on dialysis, the path from Darwin hospital to Nightcliff Renal Unit to Katherine Renal Unit is prevented by lack of compliance and lack of compliance results in referral back to hospital. Compliance is a factor determining where a person may live and has life and death consequences. At Alice Springs Hospital, not attending scheduled

dialysis sessions is interpreted as an active decision to not accept any health care including emergency resuscitation.

Acceptance on the list for access to self-care is dependent on compliance. Compliance is perceived as a key limitation on the suitability of Indigenous people for kidney transplant (IMPAKT (Improving Access to Kidney Transplant)). This may underlie the poor success of Indigenous people in acceptance onto the transplant waiting list and a lower rate of moving from the list to transplantation (Cass et al., 2003).

One of the consequences of poor compliance amongst people with renal failure, is a health crisis, which are life threatening and, when they occur in remote sites, necessitate expensive air evacuations.

We suggest poor compliance from Lajamanu residents may reflect rational decision. The only clear outcomes following a diagnosis of kidney problems is a life spent dominated by hospitals and dislocation. Thus, people are 'voting with their feet' when they choose the benefit of spending time with their families rather than early medical interventions. The costs of this decision on their long-term health are not clear to many people.

A different perspective to practitioner centred health services and their problems with compliance are provided by a patient centred approach (Russell et al., 2003). These health systems involve the patient's situation and needs taking precedence. The patient and practitioner need to achieve clear communication before agreeing on the course of action.

Detailed Plan and Budget for Lajamanu Kidney Project:

Staging and Budgets

The core of the operation is enabling return to country visits for dialysis recipients. People from Lajamanu and Kalkaringi who are currently stuck in Darwin and Katherine will travel home and have access to nurse assisted dialysis in Lajamanu.

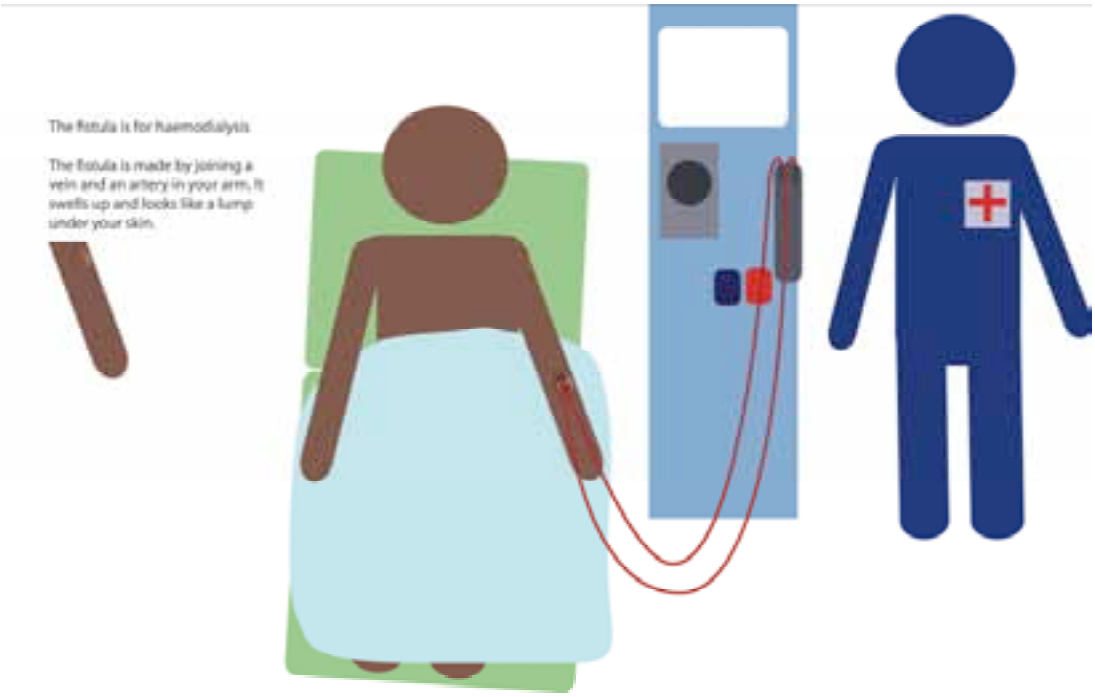


Figure 17 Fistula and Haemodialysis

The plan is presented, as three stages that need to be completed in turn

Stage 1. Employ Manager. to;

a) Seek new funds for next Stages.
b) Commence building dialysis centre.

Stage 2. Nurse Assisted Dialysis. Addressing the pressing need to start getting dialysis recipients back on country with their families. This is a 'bare bones' stage to cover transport to

and from Darwin and Katherine and to provide 2-6 week nurse assisted dialysis visits several times per year.

Stage 3. Holistic Kidney Health Service. We need to take extra care for people when they are dialysing both in towns and in home communities, especially as they get old. This includes supporting their accommodation, nutrition, transport and connection to country needs. Also, in the home communities we need to teach all the community about caring for their kidneys so that fewer people get problems and those that do can spend longer at home before starting dialysis. This will involve learning from people on dialysis and from staff, through providing a nutrition program and organising bush trips. People in Darwin and Katherine get sad and lonely which can make them sick. They need social support, especially when they first arrive to start dialysis including support for housing, transport and social events.

In preparing the budget, we have based it on two assumptions. The first assumption is that the Kurra Committee can fully fund Stage One. The second assumption is that the project will proceed over three years according to plan. By current standards in the Territory, the project will proceed at a fast pace. Through our experience in getting similar projects underway in other remote communities we believe we can coordinate the funding, recruitment and construction phases. The project has numerous risks including changes in government policies, weather emergencies and interagency frictions etc. These risks and changes are part of the environment under which we all operate.

A Role for Kurra Aboriginal Corporation

Our recommendation is that Kurra continue in its active role to get this project underway through funding in the 2010-11 year of $574,000. This will complete Stage 1 and put the project in a position to commence dialysis in the second half of 2011.

As a second option, Kurra could part-fund Stage 1 through salary support for a manager whose task would be to commence applying for all funds required and to cover governance work. This would be a minimum of $90,000 in 2010-11. This level of funding would result in a slower path to commencing dialysis.

The project involves risk for Kurra Aboriginal Corporation. Progress is very dependent on the Lajamanu Kidney Committee and the manager being successful in attracting new funds. If they are delayed or fail in progressing the project, the community and Yapa on dialysis will be waiting longer.

Funding Option 1

Table 4 Budget Stage 1. Employ Manager 2010-11

Operational Costs	Funds
Staff (see Job Descriptions below)(including on costs)	
• Manager (Full time, 8 months)	$65,000
Recruitment Manager	$5,000
Recruitment Nurses	$4,000
Accounting	$10,000
Audit	$2,000
Brokerage	$4,000
Project Expenses	$20,000
Staff Fares	$10,000
Staff Accommodation	$4,000
Governance Project	$15,500
Return to Country Project	$40,000
Office Supplies	$3,000
Computer Support	$1,000
Project Telephone	$2,000
Food	$2,000
Power, Water, Gas	$8,000
Workers' Compensation	$1,500
Vehicle - Fuel & Oil	$5,000
Vehicle- R&M	$5,000
Vehicle- Reg & Ins	$4,000
Travel Allowance	$3,000
Furniture & Fittings	$5,000
Fencing & Landscaping (renal unit area)	$5,000
Total	$224,000

Capital Costs	Funds

Capital Costs	Funds
Construction • Dialysis building. A demountable building very similar to the 2 chair/machine facility completed in Yuendumu in 2010. The builder at Yuendumu did an excellent job and has given an indicative quote for Lajamanu.	$350,000
• Vehicle Lajamanu vehicle for patient transport, stores, cultural connection trips - food, medicine, story.	$60,000
Total	$410,000

Budget	Funds
Total Costs	$634,000
Return to Country Funds from GMAAC and Tanami Gold	-$40,000
Savings from Kurra funding to WDNWPT on Scoping Study	-$20,000
Request from Kurra Committee	$574,000

Table 5 Budget Stage 2. Nurse Assisted Dialysis. 2011-2012

Operational Costs	Funds
Staff (see Job Descriptions below)(including on costs)	
• Manager (Full time, 12 months)	$100,000
• 1.6 x Nurses (one nurse on community working 6 days per week requiring leave/relief to keep service operating all year)	$184,000
Recruitment Nurses	$4,000
Accounting	$8,000
Audit	$1500
Evaluation Expenses	$15000
Medical Supplies (one off capital eg scales)	$10000
Project Expenses/oxygen	$10000
Fares Staff	$10,000
Fares (return to country)	$30000
Office Supplies	$3000

Operational Costs	Funds
Computer Support	$1000
Project Telephone	$6000
Food	$6000
Freight	$8000
Power, Water, Gas	$6000
Workers' Compensation	$2500
Industrial Special Risk	$1000
Medical Liability	$6000
Association/Medical Liability	$2000
Vehicle - Fuel & Oil	$15000
Vehicle - R&M	$4000
Vehicle - Reg & Ins	$2000
Travel Allowance	$10000
Staff Development-Orientation	$5000
Furniture & Fittings (renal unit)	$10,000
Fencing and landscaping	5,000
Total	$465,000

Capital Costs	Funds
Construction • Nurses accommodation	$350,000
Total	$350,000

Budget	Funds
Total Costs	$815,000
Income required from funders	$815,000

This budgeting anticipates receiving support for:

- Two dialysis machines, Water treatment, Technical training/trouble shooting for nurses with dialysis equipment and Dialysis equipment maintenance from Fresenius Medical Care Australia Pty Ltd through its contract with NT Government. The value of this in kind support is approximately $80,000 per annum.

∞Some support for nurse accommodation initially will be sought as in kind contribution from KWHBAC, Central Desert Shire and FaHCSIA.

Table 6 Budget Stage 3. Holistic Kidney Health Service. 2012-13

Operational Costs	Funds
Staff (see Job Descriptions below)(including on costs)	
∞ Manager (Full time, 12 months)	$100,000
∞ 1.6 x Nurses (one nurse on community working 6 days per week requiring leave/relief to keep service operating all year)	$184,000
∞ Katherine Social Support Worker (0.4x)	$25,000
∞ Darwin Social Support Worker (0.4x)	$25,000
Recruitment	$5,000
Accounting	$8,000
Audit	$1500
Evaluation Expenses	$15000
Project Expenses	$15000
Fares Staff	$14000
Fares (return to country)	$30000
Office Supplies	$3000
Computer Support	$2,000
Project Telephone	$8,000
Food	$9,000
Freight	$8000
Power, Water, Gas	$6000
Workers' Compensation	$4,500
Industrial Special Risk	$1000
Medical Liability	$6000
Association/Medical Liability	$2000
Vehicle Hire	$4,000
Vehicle - Fuel & Oil	$15000
Vehicle- R&M	$4000
Vehicle- Reg & Ins	$2000
Travel Allowance	$10000
Staff Development-Orientation	$5000
Furniture & Fittings	$10,000

Operational Costs	Funds
Fencing and landscaping	$5,000
Total	$527,000

Capital Costs	Funds
Construction • Patient temporary accommodation	$450,000
Total	$450,000

Budget	Funds
Total Costs	$977,000
Income required from funders	$977,000

Funding Option 2

Table 7 Budget. The Slow Road. 2010-2011

Dialysis Development Project

Operational Costs	Funds
Staff (see Job Descriptions below)(including on costs)	
• Manager (part time 24hrs a week, 12 months)	$68,000
Recruitment Manager	$3,500
Accounting	$1,000
Audit	$500
Return to Country Project	$40,000
Meeting and Travelling Costs for Lajamanu Kidney Committee	$14,000
Office Supplies	$3,000
Computer Support	$1,000
Project Telephone/internet	$3,000
Power, Water, Gas	$5,000
4WD car hire	$6,000
Travel Allowance	$3,000
Furniture & Fittings	$1,000
Purchase computer/printer	$2,000
Total	$150,000

Budget	Funds
Total Costs	$150,000
Return to Country Funds from GMAAC and Tanami Gold	-$40,000
Savings from Kurra funding to WDNWPT on Scoping Study	-$20,000
Request from Kurra Committee	**$90,000**

Table 8 Agreements Required Prior to Commencing Dialysis:

Agreements	Organisations
Tenure	Land Trust, CLC
Auspice covering staff employment, handling of funds, meeting schedules, corporate governance.	Kidney Committee AC and WDNWPT AC
Lot Services	Central Desert Shire
Sub-Lease of community land	FaHCSIA, Hooker Creek Aboriginal Land Trust, CLC
MOU covering integration with Growth Town developments	NTG
Development/Building/Certification	DPIFM, NTG
MoU covering patient information, protocols, biohazard waste	KWHB
SLA covering patient information, dialysis equipment, clinical guidelines	DHF, NTG

Detailed Position Descriptions for Option 1:

Manager:

The manager position will require considerable travel. They could reside in Lajamanu, Darwin or Katherine. They will spend several trips per year and at least 30 days per year in Lajamanu to ensure they are familiar with the community.
They will need an office either from their own home, the new dialysis unit once operational in Lajamanu or hosted by another organisation.

The manager would be responsible for:

- Ongoing funding
- Reporting to funding bodies, WDNWPT, Kidney committee, Health services.
- Recruitment – Nurses, support workers
- Nurses accommodation
- Wages – Staff
- Supervision of staff
- Management of budget.

Remuneration

This position is commensurate with the Aboriginal Community Controlled Health Services Award 2010, Administrative Level 7.

Subject to the terms and conditions of this contract, the Employee shall be entitled to

- A wage of $37 per hour on a permanent part time basis,
- employer paid superannuation
- six weeks annual leave.
- 10 days sick leave per annum
- There is also the option to salary package
- 17.5% leave loading

No out of hours work is expected.

Supervisor

Manager WDNWPT

Accountable to;

The Governing committee of the Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation in consultation with the Lajamanu Kidney Committee

Duties of Employee

The employee will;

- Maintain and build the capacity of the Lajamanu Kidney Committee to provide community, family and patient input into the development of the Project and to establish rules and broad guidelines for the running of the Project.
- Develop a Memorandum of Understanding between the Service, the NT Health Department and KW Health to ensure cooperative working relationships and access to client information and records.
- Progress the development of the dialysis and social support services
- Develop a clear and realistic set of annual outcomes for each of the next two operational years of the Service. These outcomes will vary for each year. Consult with the Northern Territory and Commonwealth governments about potential funding contributions towards the consolidation of the Project.
- Report to WDNWPT, Kurra, NTG and Commonwealth on the progress of the project
- Oversee project works
- Oversee project budget
- Support Social Support Workers to support Yapa dialysis recipients and their families in Katherine and Darwin and if wanted to organise short trips to country.
- Support and supervise the Lajamanu Renal nurse with the clinical support of the WDNWPT Coordinator of clinical services.
- Other activities as required in negotiation with Manager of WDNWPT

Terms and Conditions

The employee will work on a permanent part time basis of up to 32 hours per week.

Nurses:

The service agreement for the dialysis machines is that they are used 6 days per week 352 days per year. This means there needs to be a nurse positions of 1.6.

On a relief/rotational arrangement.

Appointment

The employee is appointed as Dialysis Nurse.

This position is commensurate with the Nurses Award 2010; Registered Nurse level 4, grade 1

Remuneration

3. Subject to the terms and conditions of this contract, the Employee shall be

Subject to the terms and conditions of this contract, the Employee shall be entitled to

- A wage of $73,000 pa on a permanent full time basis,
- Employer paid superannuation
- Six weeks annual leave.
- 10 days sick leave per annum
- Option to salary package
- 17.5% leave loading
- Saturdays paid at time and a half (or as time and a half in lieu as negotiated with Manager).
- Work on Public Holidays will be paid at double time or double time in lieu.

Supervisor

4. Manager of Lajamanu dialysis service with clinical supervision by the coordinator of clinical services WDNWPT.

Accountable to;

5. The Governing committee of the Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation and the Lajamanu Kidney Committee.

Duties of Employee

The employee will;

- ∞ Dialyse Lajamanu and Kalkaringi patients in Lajamanu.
- ∞ Coordinate the establishment and operation of the Lajamanu dialysis facility
- ∞ Encourage patients to learn self care
- ∞ Participate in staff meetings and planning activities when available
- ∞ Participate in organising Return to Country Activities
- ∞ Take care of WDNWPT assets
- ∞ Liaise with other organisations to ensure success of WDNWPT
- ∞ Ensure safe, high quality Going Home trips
- ∞ Work as a member of a team to ensure success of the organisation
- ∞ Maintain high levels of confidentiality and professionalism
- ∞ Other activities as required in negotiation with the manager

Terms and Conditions

7. The employee will work on a permanent full time basis up to 38 hours per week.

Patient Support Workers:

Part time based in Lajamanu, Kalkaringi, Katherine and Darwin.

- A wage of $25 per hour on a permanent part time basis,
- Employer paid superannuation
- Six weeks annual leave.
- 10 days sick leave per annum
- There is also the option to salary package
- 17.5% leave loading

No out of hours work is expected.

Supervisor

Manager

Accountable to;

The Lajamanu Kidney Committee and The Directors of the Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation.

Duties of Employee

The employee will;

- Provide and coordinate social and advocacy support for Lajamanu and Kalkaringi dialysis recipients. Prioritise support for high needs patients with complex support needs.
- Assist members with advocacy, brokerage, and social activities
- Participate in staff meetings and planning activities
- Document care in files
- Assist in organising Return to Country Activities
- Report to governing committee as required.
- Liaise with other organisations to optimise care

- ∞ Work as a member of a team to ensure success of the organisation
- ∞ Maintain high levels of confidentiality and professionalism
- ∞ Other activities as negotiated with the Manager of the Lajamanu dialysis project.

Terms and Conditions

The employee will work on a permanent part time basis.

Conclusion:

The Lajamanu dialysis project has recieved a great deal of support in these early stages. Few would argue the negative impacts of removing people from their community is ongoing for many community members, the nurse assisted model proposed in this project is a way to enable people short visits back home, while keeping people well.

Detailed Position Description for Option 2:

Lajamanu Dialysis Development Manager:

Overview:

The aim of this position is to progress plans articulated in the Lajamanu Scoping Project report to gain support and funding for establishing nurse assisted dialysis in Lajamanu, organise return to country trips and social support services in Darwin and Katherine.
Supervision: the newly formed Kidney committee and the Directors of WDNWPT through the manager of WDNWPT

Key Activities:

- Support governance and functions of the Lajamanu/Kalkaringi kidney committee
- Support return to country visits and the funding options from Lajamanu Air/Newmont
- Keep abreast of the National Dialysis study and ensure issues for Lajamanu are being considered
- Seek ABA funding for infrastructure and any other aspects of the program
- Seek DOHA funding for same
- Explore other possible funding options and develop submissions
- Liaise with the Northern Territory Government over access to machines and technical support
- Further developing relationship with Katherine West health Board
- Act as an advocate on Renal issues for the region

- Report to Kurra on progress

Essential Requirements:

- Experience working with Indigenous Australians
- Willingness to take direction from indigenous leadership
- Ability to liaise with stakeholders
- Experience in report and submission development
- Current driver's license
- Willingness to work as a member of a team and independently
- Good communication skills
- Ability to travel

Desirable:

- Qualifications/experience working in policy/ health services/ advocacy.
- Warlpiri language skills
- 4WD experience

References:

Atkinson, V. J. (2001) *Lifting The Blankets: The Trangenerational Effects Of Trauma In Indigenous Australia*. Brisbane, Queensland University of Technology.

Australia and New Zealand Dialysis and Transplant Registry, Annual Report 2009.

Carson, B. Dunbar, T. Chenhall, R. & Bailie, R. (Eds.) (2007) *Social Determinants of Indigenous Health*, Allen and Unwin.

Cass, A. (2006) The economic impact of end-stage kidney disease in Australia. IN AUSTRALIA, K. H. (Ed.), Kidney Health Australia.

Cass A, Cunningham J, Snelling P, Wang Z, Hoy W. (2003) Renal transplantation for Indigenous Australians: identifying the barriers to equitable access. Ethn Health. 8:111-9.

Davis-Floyd, R. (1992) *Birth as an American Rite of Passage,* California, University of California Press.

De Ishtar, Z. (2005) *Holding Yawulyu,* Melbourne, Spinifex.

Devitt, J. & McMasters, A. (1998) *Living on Medicine,* Alice Springs, IAD Press.

Eckermann, A.; Dowd, T.; Chong, E.; Nixon, L. et. al (2009) *Binan Goonj - Bridging cultures in Aboriginal health*, Elsevier.

Gorham, G. (2003) Prevention and Treatment Options for Renal Disease in the Northern Territory (with particular reference to the Barkly Region), CRCATH.[URL]

Grieves, V (2009) Aboriginal Spirituality: Aboriginal Philosophy, The Basis of Aboriginal Social and Emotional Wellbeing, Discussion Paper No. 9, Cooperative Research Centre for Aboriginal Health, Darwin. [URL]

IMPAKT (Improving Access to Kidney Transplant), www.crcah.org.au/research/impakt.html

McDonald S (2004) Indigenous transplant outcomes in Australia: what the ANZDATA Registry tells us. Nephrology (Carlton). 2004 Dec;9 Suppl 4:S138-43.

McEwan, A. & Tsey, K. (2009) The Role of Spirituality in Social and Emotional Wellbeing Initiatives: The Family Wellbeing Program at Yarrabah. IN COOPERATIVE RESEARCH CENTRE FOR ABORIGINAL HEALTH, G. Y. H. S., JAMES COOK UNIVERSITY (Ed.) Darwin, James Cook University.[URL]

Rivalland P (2006) It's more than machines and medicine: they should understand there's a Yanangu way: Yanangu providing their own kidney dialysis services as Indigenous people from the Western

Desert, Central Australia: summary report. Casuarina, NT: Cooperative Research Centre for Aboriginal Health. [URL]
Russell S. , Daly J., Hughes E. & Op't Hoog C. (2003) Nurses and 'difficult' patients: negotiating non-compliance. Journal of Advanced Nursing 43, 281–287[URL]
Sweet, M. (2010) The silent transition: Childbirth in Australia. PhD Thesis Southern Cross University.
Sweet, M. (2010) Evaluation of pilot back to country programme for Tanami dialysis patients, March 2010. WDNWPT.
Trudgen, R. (2000) *Why Warriors Lie Down And Die,* Darwin, Aboriginal Resource and Development Services Inc.

Appendix 1

Lajamanu trip in detail

No printed version
Contact WDNWPT.

Appendix 2

Procedure for safe dialysis back home:

Rules For Dialysis In Lajamanu:

Introduction; We are recommending a two chair dialysis unit being set up for self care and nurse assisted dialysis in Lajamanu. In preparation for this new service, there needs to be accepted rules to ensure safety and equity, enabling all dialysis recipients a fair go to get home. Based on 7 years experience of providing dialysis in Kintore, the following rules have been suggested and have taken lead from this experience. Before commencement of dialysis at Lajamanu the rules would need to be agreed to by the Lajamanu patients returning home, the committee and WDNWPT directors.

ALL dialysis patients from Lajamanu and Kalkaringi will have equal access to the machines in Lajamanu.

All visits will be of three week duration unless a shorter time is negotiated.

ALL patients will require clearance from a Nephrologist before they can have dialysis in Lajamanu.

No one who turns up in Lajamanu without an organized visit will be dialysed there. (Your dialysis MUST be arranged in Darwin or Katherine)

If you wish to dialyse in Lajamanu, you must have been attending dialysis regularly, taking your tablets and trying to stick to your fluid restriction before you will be considered for dialysis in Lajamanu. If you are having trouble with these, we can help.

You must have somewhere to stay in Lajamanu and someone to

support you for your visit.

You must come back to Darwin or Katherine when your visit on dialysis is finished so that others can use the machines.

Special requests for out of turn visits for Sorry business or community events will be considered.

You must try to do as much for yourself as possible while in Lajamanu. Our nurse will be busy dialysing 6 days a week and will not be able to provide extra support.

Missing one dialysis in Lajamanu without arranging alternatives with our nurse may lead to the suspension of your visit home and a return to Darwin or Katherine.

If you become sick in Lajamanu or your dialysis status changes, it may be necessary for you to return to Darwin or Katherine. Our nurse and the Nephrologist will make this decision.

WDNWPT will

Help you to get organised in Darwin or Katherine for your visit

Provide transport to and from Lajamanu

Provide safe dialysis in Lajamanu.

Appendix 3

List of meetings

Meetings:

Date	Who	Position	Organisation	Summary
23 June	Norbert Patrick	Chair	Central Desert Shire(CDS)	Support Dialysis Lajamanu
28 June	Malcolm	Builder	Self employed	Quote renal unit and nurse accomodation Lajamanu
29 June	Sue Greggery,	Shire Services Manager	Central Desert Shire	Support Dialysis Lajamanu
	Joyce Herbert	Member	KWHB	Support Dialysis Lajamanu, On kidney committee
30 June	Merrilyn Williams	GP, Lajamanu clinic	KWH	Supportive of project, Ideas on auspicing organisations in Lajamanu.
	Penny O'Connor	Health Centre Leader	KWH	Supportive of project without getting involved. Too busy in acute care.
	Geoffrey Matthews	Director	KWHB	Supports community dialysis On Kidney Committee
	Arts centre	Manager	Warnayaka **Art Centre**	Supportive unable to be involved financial restraints
1 July	Chrissie	Aged care coordinator	CDS	Supportive of project, potential working with aged care, deliver meals to renal recipients.
	Stewart	Store manager	Lajamanu Progress Association	Supportive of project. Offered help in meeting and contacts.
	Jim Butler	CEO	Lajamanu Progress Association	Considered proposition to auspice project

	Andrew Pratt	Manager	Lajamanu air	Supportive in getting patients home. Fees given and potential managers name.
2 July	Joan Tiballs	Nurse	KWH	Supportive, showing us around clinic, information about renal health Kalkaringi
5 July	Maureen Toner	Regional Public Health Nurse	NTG	Supportive of prevention of renal disease.
	Helen Morris	Renal recipient	self	Potential chair of kidney committee
	Louise Harwood	Chief Medical Officer	KWHB	Supportive, would take to board auspicing idea.
6 July	Mary Napurrula Rockman	Member	Kurra committee	Supportive of Dialysis at Lajamanu.
7 July	Kalkaringi and Lajamanu Renal mob in Darwin			All want dialysis at Lajamnu
	Elaine Bowen	Head renal nurse	NTG, Nightcliff renal unit	Supportive of project, risks for people returning to country.
	Karen Brown	Head social worker	NTG, Nightcliff renal unit	Supportive of project, risks for people returning to country.
8 July	Gill Gorham	Senior Nurse Renal Advisor	Department of Health and Families | Northern Territory Government.	Discussion different models of care, What NTG could potentially support for Lajamanu project.
	Renal conference		Royal Darwin hospital	Different renal service delivery and models NT
9 July	Jeannie Devitt & Edward	Health and Social Policy Consultants	Self	Research of renal in NT what's happening.

	Tilton			
12 July	Dorothy Brown	Nurse in charge of self care unit	NTG, Nightcliff, Darwin	Discussion of Self care in Top End.
14 July	Josephine Goonan Pani Weiland Robyn Dyer	Nurses in charge and nurse, Katherine renal unit OH & S representative	Renal Service, DHF, NTG	Renal at Katherine now and the future. Focus on Lajamanu and Kalkaringi patients.
16 July	Karl Hampton	Minister for Central Australia MLA Stuart	NT Legislative Assembly	Potential support for IT for Lajamanu project.
20 July	Alice Kemble	Senior advisor	Office of Coordinator General for Remote Indigenous Services	Support through LIP initiative, many ways forward.
21 July	Craig Cross, Liz Crowley and Michelle Krauer	Managers	OATSIH	Potential support for buildings available in December. Support for other areas of project possibly available after report completed.
27 July	Andrew Bell	Medical Director	AMSANT & KWHB	Supportive of project.
28 July	Marion Shaw	CNC Peritoneal Dialysis	NT Renal Services Top End Department of Health and Families, Northern Territory Government	Information exchange on Peritoneal Dialysis.
2 Aug	Kerry Dole	Transplant Nurse	NT Renal Services Top End Department of Health and Families, Northern Territory Government	Transplant services available

9 Aug	Bess Price	Warlpiri Leader and Consultant	Jajirdi Consultants	Personal and experience with PD and transplant. Family experience with renal disease.