

**“It’s more than machines and medicine
– they should understand there’s
a *Yanangu* way”**

**Providing kidney dialysis services to *Yanangu*,
Indigenous people from the Western Desert**

**A report on the activities of
Western Desert Nganampa Walytja Palyantjaku Tjutaku
*“Making all our families well”***

Paul Rivalland, on behalf of WDNWPT, January 2006

“I now want to make a statement about people, I mean about renal patients. I want to make a message, give a message to anyone who listens to this and support us with it, with the idea. We’re talking about a statement and that is –

*“People on dialysis need to get back out there to their communities for cultural reasons, to be there with the family, to be there with the other relations, and make themselves happy. All the renal patients should have this chance to go out and have a visit”.
So we need to know that. We don’t have any hope for us, for ourselves, we are supposed to have a dialysis machine out in the community. That way people can be happy, in their country and with their family. That’s a message I wanted to give, that’s my personal message, I don’t know what the other people think. If nobody’s going to say something about their own lives they should say. But, I am talking, also for myself and for those people, for those renal patients this is the message I am giving”.*

Smithy Zimran Tjampitjinpa (1958–2001)¹

In the NT there is a hidden cost burden in taking people to services rather than services to people. There are very stark and obvious examples of this type of cost burden when people in need of care are taken to urban centres for treatment. In many cases they are followed by extended family, stays become indeterminate and associated with the added social costs of homelessness, alcohol and drug abuse, and at the same time there is a negative impact on the community from which they come.

Banscott Report 2003²

“I went for a three week holiday and stayed with family, which was great. Having the machine at Kintore gave everyone happy faces. ‘Oh you’ve been in town such a long time’ they said, ‘Finally seeing you up close has made us happy.’”

Amy Nampitjinpa, 9/04, the first WDNWPT member to return home on dialysis.

Frontespiece: title quote from Bobby West Tjupurrula, WDNWPT Chairman (9/04)

Main Messages

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- *Yanangu*, the Indigenous people from the remote cross-border Western Desert region of Central Australia (Northern Territory and Western Australia), endure the highest rates of kidney failure in Australia. Until recently, regional systems required those needing dialysis to shift to Alice Springs to receive treatment, where currently the 27 WDNWPT members form around 20% of all those on dialysis in the renal dialysis unit (RDU).
- The imperative placed upon *Yanangu* on dialysis to leave their communities promotes ‘dislocation’ – their disconnected experience of institutional life in Alice Springs. *Yanangu* emphasise the struggle to hold on to their identity, expressed through fundamentals of family (*walytja*), country (*ngurra*) and Dreaming (*tjukurrpa*). Maintaining such interconnections are central to individual and community cohesion, health and well-being.
- Providing effective, quality renal services to *Yanangu* on dialysis requires a holistic approach addressing ‘dislocation’. Respect, understanding and incorporation of these *Yanangu* values will achieve services that are more than just machines and medicine.
- In 2000, *Yanangu* raised just over \$1 million at an auction of collaborative and donated Indigenous artworks, to determine their own solutions through establishing WDNWPT. They received no government support for the first 3 years of operation, and as such represent a unique partnership and successful example of Indigenous self-determination.
- Financial independence enabled existing *Yanangu* capacity to create its’ own appropriate, effective solutions. The Governing Committee of senior *Yanangu*, including dialysis patients, has developed and instituted a unique model of community-based renal service provision, incorporating *Yanangu* cultural values, an approach known as ‘*Yanangu Way*’.
- ‘*Yanangu Way*’ promotes the centrality of individual and community wellbeing as understood from an Indigenous viewpoint, and puts this into practice through services promoting family and community connectedness and *Yanangu* identity.
- ‘*Yanangu Way*’, as operationalised by WDNWPT, has underpinned the development of appropriate and effective solutions for the provision of renal services to *Yanangu*, shown to be both clinically and culturally safe through ongoing monitoring.
- WDNWPT has developed and instituted services, supported by active monitoring:
 - a) ‘Lifelines’– 2 programs committed to immediate assistance; ‘YAM’ providing advocacy and social support; ‘Return to Country’ providing regular visits home to reconnect with families. These demonstrate quantifiable health and economic benefits to the Acute Care system, alongside the reinvigoration of *Yanangu* optimism and self-worth.
 - b) ‘Longterm’– 2 contrasting programs to change the context of service delivery; ‘Going Home’ offering safe, supported dialysis for periods at home. Preliminary outcomes are positive; ‘Bereavement’, an unfinished process of grief resolution.
- WDNWPT describes multiple deficiencies in health management quality along a pathway of care involving primary and tertiary health services in town & out bush, exacerbated by jurisdictions of Commonwealth and Territory funding. For *Yanangu*, it took just over 2 years to deteriorate from first community diagnosis of renal disease to need dialysis in town, entering the Acute Care system poorly-prepared and in crisis.
- Ongoing work is required in three key areas.
 - a) To shift the primary financial responsibility for provision of activities associated with the ‘*Yanangu Way*’ from *Yanangu* communities to the health system.
 - b) To address deficiencies in health management quality along the pathway of care
 - c) To ensure health service delivery meets expressed *Yanangu* needs

Executive Summary

Background: By 2000, *Yanangu*¹ from the remote, cross-border region of Central Australia were so dissatisfied with the deleterious effects of mainstream renal services, that they took the initiative and raised \$1 million through an art auction at Sotheby's, Sydney. The total amount has been used to establish Western Desert Nganampa Walytja Palyantjaku Tjutaku, an Aboriginal Corporation, whose title means “*Making all our families well*”.

Yanangu focus was to reverse ‘*dislocation*’, their cumulative experience when obliged to leave behind their homes and families to receive haemodialysis (HD) treatment for renal failure in the regional dialysis unit (RDU) in Alice Springs. Rather than a smooth, electively managed transition onto dialysis over a couple of days, WDNWPT members at this late stage are poorly-prepared medically and personally, and arrive in crisis, requiring catch-up fistulas and 3 weeks in intensive care and hospital. Alone, unwell and disconnected from family support, *Yanangu* then struggle to make robust treatment and life-choices. They enter institutional haemodialysis by default, itself the most expensive treatment option, where they become utterly dependent in the alien community of Alice Springs. *Yanangu* describe a twilight existence in town, without hope, starkly defined by statistics of reduced survival (≈ 2.5 yrs). *Yanangu* regard the restoration of all these affected by dialysis as pivotal to maintaining healthy, vibrant, coherent families and communities, both in town and out bush.

Alongside Indigenous populations globally, *Yanangu* are most affected by high incidences of renal disease determined by rapidly-changing lifestyles, relative poverty and disadvantage. Regionally, the high levels of accompanying co-morbidity, especially type-2 diabetes and ischaemic heart disease, help drive Chronic Kidney Disease (CKD) development in the population, and a burgeoning regional need for Renal Replacement Therapies (RRT). WDNWPT investigation has shown dialysis prevalence of 6200 pmp, 20 times national figures, predominantly women in their early 40s and 50s, representing the highest recorded rates of kidney failure in Australia. Currently WDNWPT supports 27 members on dialysis (1/06), around 20% of those on treatment in RDU, where overall 75% are people from remote areas.

‘*Yanangu and WDNWPT Ways*’: The authoritative body within WDNWPT is the Governing Committee, comprising 11 senior *Yanangu* men and women, including dialysis patients, who all share experience of illness, activism and being *Yanangu*. They stress the way ‘*dislocation*’ directly damages *Yanangu* individual and family identity and well-being, as expressed through connected notions of *ngurra* (home; country), *walytja* (family) and *tuḷku; tjukurrpa* (ceremony; Dreaming). All developments to address *Yanangu* needs to nurture well-being must be grounded in this ‘*Yanangu Way*’, including renal dialysis services. The report uses the term ‘*Yanangu Way*’ to express this self-determination and existing capacity.

The resolve of the *Yanangu* members of WDNWPT to determine their own viewpoint is central to the success of WDNWPT, and has been critically supported by philanthropic financial autonomy. No financial support from government was received over the first 3.5 years of operation, which included the planning and institution of all current WDNWPT services (cost \$470,000 approx.).

To operationalise the values contained within ‘*Yanangu Way*’, WDNWPT shows sustained attention to appropriate development and governance, developing secure relationships through careful advocacy, whilst seeking to avoid jeopardising the care of members currently on dialysis. Particularly heavy investment is made in inclusive stakeholder relations to work for change with the larger, powerful mainstream renal service organisations. This approach, referred to in the report as ‘*WDNWPT Way*’, costs \$50,000/yr (approx.).

¹ *Yanangu* – the term by which Indigenous people from the area refer to themselves.

Developing solutions:

i) 'Lifelines'

a) 'Yanangu Advocacy Malpa' ('YAM'): Initially provided practical pastoral and spiritual support to the 'family on dialysis', including a successful 'Renal Choir'. Increasing client numbers have shifted emphasis by 2 p/time workers to more active advocacy and early intervention, ensuring access to basic entitlements, a consumer group and 'Australian Volunteers' program. Cost: \$70,000/yr (32 hrs/wk + transport), plus \$40,000 (in-kind).

b) 'Return to Country': Offers free return travel home, 6 times/year for all WDNWPT members, coordinated with routine dialysis in RDU. Cost: \$50,000/yr (\$1908/person/yr).

Outcomes: Broad documented health benefits have developed. WDNWPT members now attend routine dialysis significantly better than their counterparts. They require dramatically fewer RFDS emergency evacuations from remote communities (savings estimated at \$111,000). Reduced hospitalisations associated with dialysis result in actual cost-savings to the Acute Care system, with the cost/person month of acute hospital care declining from \$373 to \$268 (savings of \$61,000). *Yanangu* emphasise the vitality and optimism experienced by all as family networks are re-established. As 'YAM' continues, concerns have grown at the withering capacity of RDU Social Work services in contrast to WDNWPT progress.

ii) Long-term programs

a) 'Going Home': A service offering 6 weeks of (reverse) respite away from RDU. A WDNWPT 'Selfcare Trainer' (RN) supports 1–2 members on dialysis for 3 weeks in a 'Dialysis House' in suburban Alice Springs, followed by 3 weeks at Kintore in a 'Dialysis Room' within the local clinic. A second team follows in rotation. In contrast to the mainstream, all members are offered rotations, whatever their dialysis choice or skills. WDNWPT cost: start-up – \$250,000; recurrent \$50,000/yr; NT DHCS contributes \$150,000/yr for 2 RN wages recurrently (from 3/05), following successful pilot (11/04).

Outcomes: WDNWPT completed an extensive 2-yr period of consultation, infrastructure review, planning and regional negotiation to establish 'Going Home', and in 9/04 the first WDNWPT member successfully dialysed out bush, without government funding. Preliminary monitoring shows that over the first 9 months a total of 18 members, have received 144 dialyses safely, with 99.3% attendance (vs. less than 85% overall in RDU). *Yanangu* interviews are extremely positive, highlighting the physical presence of machine, peers and staff as offering an optimistic, informed focus for young people and those with renal disease from across the region. A preferred model of dialysis delivery, it strongly supports the necessary rebuilding of family cohesion.

b) 'Bereavement': Over the last 3 years, a challenging negotiation process with NTDHCS has been undertaken to address particular concerns raised by 5 WDNWPT families concerning the deaths of relatives on dialysis. Their expression of unfinished personal grief, identification of systemic problems and the resultant injury this causes immediate family, also has a continuing negative impact upon those engaging Renal Services. Acknowledging the complexity and distress such a process would encounter, WDNWPT has invested \$50,000 to develop an inclusive process and share disparate cultural views to reach a satisfactory conclusion for all.

Outcomes: Unfortunately initial positive progress has stagnated over the past 7 months, and WDNWPT feels prospects for negotiation have slipped away, leaving uncertainty and hurt expressed by members.

iii) Monitoring

Alongside routine internal governance, WDNWPT invested \$100,000 over 18 months to fund 2 researchers to carry out qualitative and quantitative monitoring of its activities for fundholders and members. It was assisted by seeding grants of \$20,000 from the CRAH and \$26,000 from NTDHCS, plus considerable in-kind expert support. This report is one outcome.

Discussion: The initial philanthropy gave *Yanangu* a secure resource and an unusual opportunity to exert control over a process to develop both an understanding of issues and then institute services to meet their own needs to improve health. By building on existing capacity (*‘Yanangu Way’*), WDNWPT developed and consolidated regional networks to provide culturally-safe services with demonstrable positive benefits. The next steps are:

- the demonstrated impact of *‘Return to Country’* ought to see at minimum WDNWPT receive funding, and best an expanded pilot program in Central Australia
- the deficiencies demonstrated by *‘YAM’* require funding support for WDNWPT and an investigation as to impact upon quality of life and the cost-benefit links to health systems
- having established positive but preliminary outcomes, WDNWPT should be supported to investigate *‘Going Home’* more fully re broader impacts upon CKD and dialysis populations

Alongside regional governance developments and systematic monitoring, WDNWPT undertook protracted negotiations with government stakeholders, to engender serious funding responses. Again the initial philanthropy has supported WDNWPT to develop sufficient organisational capacity to respond to all these recurring demands of bureaucratic institutions, and aspire to equality in partnership rather than subservience. Maintaining this capacity is crucial and remains entirely WDNWPT-funded. Financial restraints have left the part-time Manager to support nearly all governance developments, informed debate and stakeholder advocacy. Currently the Commonwealth is discussing Social Responsibility Agreements (SRA), but the political context of these seems most fluid and indeterminate.

- Most likely, secure relief will not appear until the next philanthropic appeal in 2006.

Serial tensions exist due to jurisdictional differences between Commonwealth and State, and their concomitant primary and tertiary health care responsibilities to renal services and dialysis. WDNWPT investigated the *‘pathway of care’* experienced by its members as they progressed from CKD out bush to dialysis in town, a period startlingly brief (~2 yrs). A lack of integration between primary and tertiary services, inattention and poor functional quality, reduced the opportunity for *Yanangu* to meaningfully engage with CKD treatment and RRT. These shortcomings meant entering the dialysis system in crisis – resentful, inadequately prepared medically and socially, requiring lengthy acute care in hospital followed by *‘default’* institutional haemodialysis, the most expensive RRT option. WDNWPT maintains the legacy of this sub-optimal management contributes greatly to the oft-quoted *‘poor Indigenous dialysis outcomes’*, and ultimately inflated costs to health systems, *Yanangu* and broader society. In this light, WDNWPT sees several opportunities to address the quality of care:

- supporting consumer advocacy within RDU, including WDNWPT *‘Patient Meetings’*
- a strategic shift viewing RRT as an appropriate chronic disease treatment, requiring resource allocation to PHCS supporting CKD, particularly ESKD & RRT *‘outreach’* discussions
- a similar debate to deliver PHC *‘inreach’* to RDU supporting *‘holistic care’*, currently the prerogative of hospital nephrologists

Overwhelmingly, the effects of cultural dislocation are identified as the most serious cost of well-intended services to *Yanangu*, contributing to fragmentation of individual, family and community. All WDNWPT activities are aimed at reducing dislocation and meet expressed needs. The developing challenge has been to identify essential *Yanangu* and organisational characteristics underpinning solutions, and translate these for stakeholders, especially government, to determine how best it can be both encouraged to meet stated responsibilities, whilst addressing uncertainties in its’ own capacity to respond to a different world-view.

To address these issues, ongoing work is required in three key areas:

- Shift fiscal responsibility for *‘Yanangu Way’* activities from communities to health system
- To address deficiencies in health management quality along the pathway of care
- To ensure health service delivery meets expressed *Yanangu* needs

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How to use this report

This lengthy report is a resource document, providing a detailed account of WDNWPT development and an investigation of its activities from inception in April 2001 to mid-2005. In 2 sections, the main body of the report is fleshed out by nine extensive appendices. The attempt has been made to provide a first-hand description of events where possible for those who are interested in the story, to go beyond quantitative academic treatise or ‘dot-point’ summaries. In the same vein, whilst a systematic investigation was undertaken, the methods and data collection have been placed together towards the end, taken up in greater detail within the discrete appendices. Data was freely offered by participants and every effort has been taken to acknowledge and maintain individual confidentiality throughout. Both the author and Jeff Hulcombe were employed by WDNWPT alongside their roles as investigators. Share and comment upon the contents freely, but please acknowledge WDNWPT ownership responsibly.

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The investigation was aided by Gai Wilson and Jon Willis (La Trobe Uni), with financial contributions from CRCAH (\$20,000 seeding grant–2/04) and NT DHCS (\$26,000–4/04). More recently CRCAH, with particular support from Mick Gooda, Jenny Brands and Barbara Beacham, provided a \$35,000 Research Transfer grant to allow the author to finish, print and feedback the report. Since the inception of WDNWPT, the ‘Donor Committee’ (Hetti Perkins, Tim Klingender, Colin Laverty and Peter Toyne) and Paul Sweeney (Papunya Tula Artists) have always given generously of their time and energies.

Andrea Rolfe and the staff at Flynn Drive (RDU) have offered much personal help, whilst John Wakerman (Centre for Remote Health), staff and Committee at *Waltja Tjutangkku Palyapayi*, Fred Ordynski and Gill Gorham all provided crucial support and brokerage.

To all of them, a host of others involved and the *Yanangu* participants, thank you.

Fig. 1. WDNWPT Governing Committee (6/05)



Back row (L–R): Kathleen Whisky Nungurrayi, Lorna Brown Napanangka, Nancy Wheeler Napangati, Palita Wakuri Napurrula, Bobby West Tjupurrula, Marlene Spencer Nampitjinpa, Nora Nelson Napaltjarri
Front row (L–R): Desma Kantamarra Napaltjarri, Marilyn Nangala, Bundy Rowe Tjupurrula, Violet Kantawarra Nakamarra

Introduction

WDNWPT is an Aboriginal organisation representing Indigenous people on dialysis from the cross-border Western Desert region of Central Australia (NT/WA). The *Yanangu*³ people who live in this disadvantaged, remote region, endure the highest rates of kidney failure in Australia, and until recently have had no choice but to move to Alice Springs to receive dialysis treatment. The effects of this shift are so negative upon the health of individuals, family and community, it is best termed a ‘dislocation’. Dissatisfied with the effects of mainstream services, *Yanangu* took matters into their own hands.

One evening in November 2000 at Sotheby’s in Sydney, Australia, social commentators Rampaging Roy Slaven and HG Nelson compered an extraordinary auction of 35 donated Aboriginal artworks. Just over \$1 million was raised from national and international participants, simply donating or bidding for works including four specially-commissioned collaborative masterpieces from the communities of Waḷungurru (Kintore) and Kiwirrkurra. It was the culmination of over 12 months donated effort by a unique partnership of supporters, including those involved in the Indigenous art industry, *Yanangu* on dialysis, local politicians and Indigenous primary health services.⁴ The money was intended was to assist *Yanangu* on dialysis to return to their homes on appropriate treatment,⁵ and was subsequently used to fund Western Desert Nganampa Walytja Palyantjaku Tjutaku, literally “*Making all our families well*”, to realise these *Yanangu* ambitions.

Much later, Marlene Nampitjinpa (WDNWPT Executive Committee) summarised the *Yanangu* viewpoint typically:

*“This is why we’re trying tell all the people. Yanangu people, they love the patients, they want to keep them here and die in front of family, close to country and Dreaming. That is why we’re trying to fight for this machine. This is important for people. People want to see them come back – dialysis people – back to country, back to home, back to family.”*⁶

WDNWPT undertook lengthy community consultation, whilst providing immediate ‘Lifeline’ services supporting *Yanangu* on dialysis in town and assistance for regular visits home. By 9/04 it provided the first dialysis treatment for *Yanangu* at Kintore as part of a routine program. It entirely funded establishment and all services from 4/01 to 11/04. Since then it has continued to seek philanthropic and government funding to support *Yanangu* solutions. It is this struggle, and the clear health benefits that *Yanangu* ascribe to re-establishing living relationships with country, home and family, that is the focus of this report.

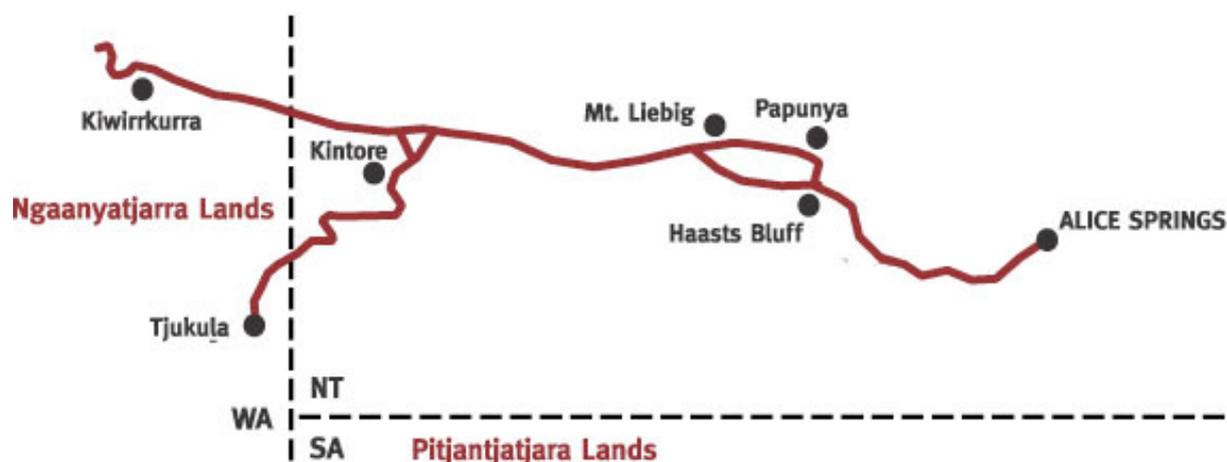
Overview of current WDNWPT activity

Currently WDNWPT is an incorporated Aboriginal organisation directed by an 11-member *Yanangu* Governing Committee, run between several remote Western Desert communities and Alice Springs. Members are identified by traditional kinship, with 26 individuals and their families on dialysis in the Alice. Two town-based ‘Lifeline’ programs operate simultaneously: ‘*Yanangu Advocacy Malpa*’ (‘YAM’) (p.33) provides social support and early intervention for members, predominantly through two dedicated, part-time workers supported by WDNWPT Management; ‘*Return to Country*’ (p.37) offers regular, short visits home to those on dialysis. By 9/04, a longer-term strategic development ‘*Going Home*’ (p.41) began to deliver dialysis training and treatment to members, taking them for 3-week treatment rotation in a ‘Dialysis House’ in the Alice Springs suburbs, then a further period out bush in a ‘Dialysis Room’, some 500 km west in Kintore at the local clinic. Two full-time specialist nurse-trainers (RN), employed by WDNWPT and subsequently recurrently funded by DHCS are responsible, working closely with RDU clinical management teams.

A part-time Manager and Community Development/Research worker based in Alice Springs have provided the glue supporting all these activities, and assisted the governance and advocacy developments required across the WDNWPT region. The part-time project coordinator (author), based in Darwin, initiated development from 4/01, subsequently co-ordinated strategic progress and monitoring, of which this report represents the end of the position. In addition, the Community Development position has ceased due to limited funds.

Though \$1 million raised seems a lot, from the earliest stages it was clear that whilst WDNWPT would always need to inform members of progress, the increasing involvement of stakeholders was necessary to build a case for recurrent, external government funding, in effect a life after philanthropy. Moreover it became clear that WDNWPT would have to fund the entire process of planning, development and service inception for an unknown period, then monitor and present outcomes to stakeholders, if *Yanangu* were to reap sustained benefit from the initial finances raised by receiving recurrent government support. This report describes the period until 5/05, but includes more recent, relevant monitoring data. The recent funding developments with the Commonwealth, including Social Responsibility Agreements (SRAs) are not covered. In 2006 further philanthropic fund-raising activity will recommence.

Fig. 2. Map of remote communities in WDNWPT area



1 The initial situation confronting WDNWPT

The situation in the period after the auction can be depicted within three linked areas:

- there were confronting descriptions of the loneliness, anguish and difficulties facing the *Yanangu* members on dialysis in Alice Springs. Urgent responses were required to offer compassionate assistance
- any new organisation would be delivering services within a complex regional context of kidney disease, health and associated stakeholders
- to meet *Yanangu* needs, the development of an organisation was required, blending service delivery and advocacy, within a responsive governance structure

The following sections address these:

- 1.1 'Dislocation' – the *Yanangu* experience of dialysis
- 1.2 End-Stage Kidney Disease (ESKD) in the WDNWPT region
 - 1.2.1 Overview
 - 1.2.2 The period before dialysis
 - 1.2.3 On reaching dialysis
- 1.3 WDNWPT development through '*Yanangu Way*' and '*WDNWPT Way*'
 - 1.3.1 '*Yanangu Way*'
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1.1 ‘Dislocation’ – the *Yanangu* experience of dialysis

The traditional country of WDNWPT members lies in the remote cross-border region of NT/WA, west of Alice Springs.⁷ It is an arid landscape, dominated by mesa outcrops, sandhills, spinifex plains and ephemeral waters. Although geographically dispersed, *Yanangu* maintain strong links through kin and extended family networks, alongside shared rights in country.⁸ In Central Australia, the health system requires the majority of *Yanangu* dialysis patients, carers and/or families to move from their homes on small, remote communities to Alice Springs for treatment. Arriving at hospital in crisis, often angry, resentful and critically unwell, *Yanangu* are ill-prepared for life on dialysis.

Since 2002,⁹ WDNWPT emphasised that this cumulative experience was best described through a migrant prism of ‘dislocation’ rather than muffled ‘relocation’. It is a schism, an abrupt and profound separation from all that was familiar and sustaining, all that went before. *Yanangu* describe how ‘dislocation’ strikes at the very core of their identity, disrupting linked values of family and relatedness (*walytja*), country (*ngurra*) and Dreaming (*tjukurrpa*), the basis of *Yanangu* well-being. The enforced disconnection of individuals and family is central:

*“For Aboriginal people in Central Australia, family and kin relationships constitute social and community life in a fundamental way; family life is social life; conversely without family there is no society, no community.”*¹⁰

Yanangu consistently describe the entangled, debilitating sadness, insecurity and loneliness brought on by being so far from country and family. It is culturally inappropriate and unwise to always remain in one place, especially in another Aboriginal person’s country,¹¹ where social, spiritual and nutritional activities are lacking, eg. hunting. With the frustration and emptiness of boredom, reduced networks and lost opportunities, individuals can wait endlessly for visits or even a familiar face:

*“... All those sorrowful people, they’re living in town with too much worry, getting sick at (name of hostel), living in one place, not going to Kintore and their family’s not seeing them. Sitting outside, they’re looking for their family, becoming lonelier and lonelier. They then just go back inside their room and think, “My family isn’t coming from Kintore.”*¹²

A lack of dependable, supportive accommodation exists to provide a stable, harmonious place to live – a pre-requisite to keep regular, scheduled dialysis attendance. Contrast the institutional existence in a one-room hostel with the feelings expressed here:

*“Yanangu like the open space of their land, where they can smell the Spirit, the wildflowers and other plants. They want fire for the smell of woodsmoke going through the air. They want to smell flowers after rain.”*¹³

Relatively poor, individuals have great difficulty in maintaining the obligatory, reciprocal gifts of money or food and shelter to relatives, exacerbating their marginalisation. Marriages crumble, kinship and ceremonial obligations can't be met, disempowerment, even emotional disintegration result. WDNWPT members describe the ensuing loss of spirit,¹⁴ a state of physical weakness and illness, noted by relatives and Renal Unit staff alike:¹⁵

*“I arrived here and have no way to leave this place. It's as if I'm in a deep valley and can't see the countryside. I feel claustrophobic. This big rock has hemmed me in and I'm claustrophobic. I didn't know what to do. I was thinking, “Oh, when will some of my family come and see me?”*¹⁶

Members of the Governing Committee, the core body of WDNWPT, described at interview the wretched situation of those on dialysis in Alice Springs as similar to that experienced by earlier *Yanangu* generations. For the Pintupi, intensive colonial contact is a recent experience, from 1950–60s being brought in by DAA and the government settlement at Papunya,¹⁷ to the mid-80s with a 'last' group walking into Kiwirrkurra. The consequences have been complex, disastrous for many, and detailed in a number of varied sources, including some *Yanangu* voices.¹⁸ Bobby West Tjupurrula (WDNWPT Chairman) gave a contemporary rendition of this protracted dislocation,¹⁹ linking the enforced settlement experience of his grandfathers', fathers' and his own generations to the ensuing development of diabetes and renal disease in *Yanangu* society. He emphasises the dysharmony of compulsory co-habitation with other language groups and lack of hunting access, with more recent ideas of junk food and lack of exercise. In particular he highlighted the 'shame' (*kunta*) of living and dying in someone else's country:

“Because it was another place. Many of their family died, like young brother, sister, auntie and many old women and many others. Staying too long, we lost our grandmothers and grandfathers. All those first people died in Papunya, in another place.” (ibid)

In response, *Yanangu* elders re-established autonomy in 1982 by moving families westwards towards Kintore - their traditional country, away from that 'sorry' and shameful place:

“... They couldn't hold onto their country while living in someone else's. You can only hold on to country by being close, because of their Tingari Dreaming ... They said ‘Our Dreaming is a long way away, we're sitting here being shamed in another country.

We'll travel a long way, we will sit close by it to be healthy'. They came here and sat close, looked after it and they were strong.” (ibid)

For families to remain healthy, elders required future generations to take-up responsibilities for looking after country and Dreaming, literally stated as ‘to hold on tight’.

The current experience of ‘dislocation’ when on dialysis in Alice Springs is complex, wide-ranging and affects *Yanangu* variably. It is not purely a geographical function of being in town. Some *Yanangu* seem to cope better than others, perhaps ‘institutional survivors’, but all express a compromised quality of life. The premature loss of key individuals to dialysis or death, places severe stress upon the transmission of cultural knowledge and societal coherence. The restoration of *Yanangu* on dialysis to their families is crucial to maintaining healthy communities.

“People on dialysis need to get back out there to their communities for cultural reasons, to be there with their family, to be there with other relations and make themselves happy.”²⁰

This clear statement from S. Zimran summarises the associations of place, culture, family and well-being and alerts non-Indigenous people to where solutions might be found. To prevent or reverse the effects of ‘dislocation’ would become the primary WDNWPT focus.

1.2 End-Stage Kidney Disease (ESKD) in the WDNWPT region

1.2.1 Overview

1.2.1 a) The regional need for dialysis

Dialysis is one downstream point along a pathway of chronic disease care, specifically Chronic Kidney Disease (CKD). Upstream, kidney function begins to deteriorate, though its’ precise time of onset is difficult to establish, making duration uncertain. End-stage kidney disease (ESKD) is reached when kidney function is reduced to 5% of normal, and requires Renal Replacement Therapy (RRT) to sustain life, of which dialysis is the most common.

Globally, Indigenous populations are most affected by the highest incidences of kidney disease – those experiencing rapidly changing lifestyles, relative poverty and disadvantage,²¹ accelerating particularly over the last 2–3 decades.²² Australia is no exception, where the highest rates of CKD and ESKD occur within the remote, regional, Indigenous environment of excess socio-economic disadvantage.²³ Of the top four worst-affected ATSI regions nationally,²⁴ Warburton and Apatula, (3rd and 4th), straddle the WDNWPT area.²⁵ With limited infrastructure of significantly

reduced quality,²⁶ the regional population has extremely poor health, low levels of formal education and little or no employment.²⁷ Social and psycho-social problems are pervasive, including alcohol and substance misuse. Not all Indigenous groups are affected equally by ESKD, with a recent, rapid rise in the NT compared to NSW,²⁸ leaving NT rates some 30 times the national figure.²⁹

Indigenous ESKD is directly influenced by the presence and severity of particular co-existing conditions, especially type-II diabetes, and hypertension/ischaemic heart disease.³⁰ With almost half of all new ESKD now attributed to type-II diabetes nationally, and with increasing numbers of diabetics regionally, there is a burgeoning requirement for RRT in the NT compared to the rest.³¹ Appendix 1 illustrates how this affected one remote health service. The cause of ESKD is not simple. A multifactorial aetiology has been proposed,³² including diverse determinants such as diabetes, socio-economic disadvantage,³³ low birthweight and institutional racism, which all affect societies in complex ways. Devitt & McMasters seminal work³⁴ describes the Central Australian Indigenous perspective of causation through the dramatic changes wrought since colonisation. Here in this WDNWPT report, *Yanangu* describe how processes that undermine individual and community coherence and well-being, including well-intentioned dialysis treatment services, disrupt ‘*Yanangu Way*’ (see p.26), which contribute to and causing ill-health.

1.2.1 b) *Yanangu* knowledge of renal disease & services

In 4/01, *Yanangu* working to set-up WDNWPT (see Appendix 2) had an uneven knowledge of renal disease and existing dialysis services. It focused upon the personal ‘dislocation’ experience of family members on institutional haemodialysis (HD) in the Renal Dialysis Unit (RDU) in Alice Springs, voicing concerns over poor survival and quality of care in comparison to their non-Indigenous counterparts. Confirming the persistence of the information vacuum described by Devitt and McMasters in “*I only understand half*”,³⁵ *Yanangu* frustration was compounded by their inability to influence existing non-Indigenous biomedical views of disease causation and service, to meet their needs:

*“The nurses don’t realise why the renal patients die, because people worry for their family, for their country, and to be there with the family close by. That’s why they get worry and stress, they get a lot and they get sick because of thinking, you know.”*³⁶

CKD is usually symptomless, with kidney function identified during routine clinical consultations for a number of conditions, including diabetes, using blood tests to calculate physiological endpoints, e.g. Glomerular Filtration Rate (GFR). The NT has adopted

international guidelines staging deteriorating kidney function (failure), which in turn are linked to intervention opportunities by PHCS and NT Renal Services using accepted regional protocols such as the CARPA Standard Treatment Manual.³⁷ Such protocols are informed by important regional evidence that CKD can be successfully slowed or halted by PHCS which receive additional funding to focus upon tight blood pressure control and engage community support.³⁸ Fig. 2 illustrates the chronology of such delay, whilst Fig. 3 overlays CKD deterioration with health service responsibilities.

Fig. 3. Delaying CKD deterioration

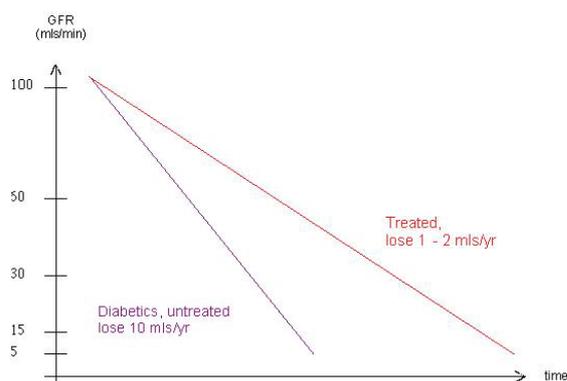
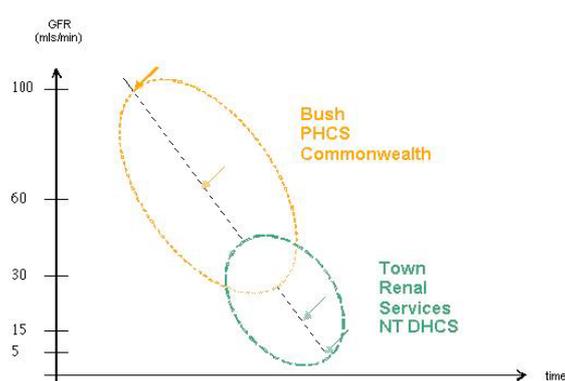


Fig. 4. Health service jurisdictions and CKD



The arrows in Fig. 4 mark particular stages of kidney failure and interventions as required by CARPA STM protocols. The intersection of service responsibilities represents the important primary and tertiary interface, where PHCS and NT Renal Services share care as *Yanangu* approach the need for dialysis.

1.2.1 c) Jurisdictions of renal service delivery

Within the WDNWPT region, health and other service co-ordination is complicated by a multiplicity of fundholders, providers, and programs operating at the junction of Tristate jurisdictions.³⁹

i) Federal responsibilities: The Commonwealth manifests its' responsibility through funding the activities of several PHCS in remote communities within the WDNWPT region: Ngaanyatjarra Health (NHS) along the eastern border of WA, Pintupi Homelands Health Service (PHHS) in Waḷungurru,⁴⁰ with NT Remote Health servicing the other relevant communities. Alongside acute medical care in the primary setting, PHCS are responsible for secondary prevention. If primary prevention is the 'big picture' (relief of poverty etc.), then a secondary definition relates to the screening, detection and management of the further deterioration of CKD. Importantly this includes care of co-morbidities such as diabetes and ischaemic heart disease, in particular the aggressive control of raised blood pressure.⁴¹

More recently, the Commonwealth has provided extra, targeted support for remote clinics by funding Physicians and other specialists to visit via the Medical Specialist Outreach Program (MSOP).⁴² *Yanangu* with kidney disease (or other conditions requiring specialist referral), are referred to these visits or relevant clinics either in Kalgoorlie or Alice, depending on the PHCS location. If acutely unwell, they are evacuated to regional centres (Perth, Alice Springs or Adelaide).

In Alice Springs, Central Australian Aboriginal Congress (CAAC) is the major Indigenous PHCS, and counts individuals from bush as permanent clients after 6 months of their living in town. The organisation has no formal ‘in-reach’ to RDU, where ‘holistic’ chronic disease care is designated by DHCS as the responsibility of the nephrologist.

ii) State and Territory responsibilities: NT Renal Services are funded from within the NT ‘Acute Care’ stream, activities associated with hospital-based services. Broadly-speaking, such services associated with ESKD are initiated at a physiological measurement of kidney function deterioration, where GFR = 60–30 mls/min (mild kidney disease / failure).⁴³

Whilst acknowledging the importance of upstream prevention, especially through its’ Preventable Chronic Diseases Strategy (PCDS)⁴⁴ and related activities, the major expensive activity comes downstream, reacting to the large numbers of Indigenous people entering Alice Springs requiring long-term dialysis. Any prevention activity by Renal Services is ‘tertiary’ in nature, ie directed to prevent and control established ESKD complications.⁴⁵ In 2001, Top End and Central renal services operated with excessive autonomy, with the historical development of NT services considered both controversial and *ad hoc*.⁴⁶ In Central Australia, there were professional and organisational concerns including dialysis quality and reduced survival, increasing costs, and the narrow focus on centre-based haemodialysis in contrast to national developments (ibid).

The quality of integrated care across this interface has specific implications for WDNWPT, as discussed in the following sections.

1.2.1 d) Local context

By 2001, the effect of tripling numbers on dialysis in the NT since 1994 had severely stressed the existing strategic response to renal service delivery in Central Australia, with its’ historic focus upon institutional HD within regional centres and active discouragement of community-based dialysis.⁴⁷ This was in stark contrast to the national situation, particularly WA, where a remote dialysis program has been developing for over a decade. A lack of integrated regional policy and political will to co-ordinate responses,⁴⁸ plus increased workload and staff turnover

within RDU (Alice Springs), added to a developing sense of isolation, frustration and crisis for staff and patients.

Specific local difficulties existed within RDU in 2001, as described at WDNWPT interviews during its' systematic investigation.⁴⁹ Rigid approaches to medical staffing arrangements lead to excessive CKD outpatient appointments, frequently not attended, with a focus upon medical prescription. In contrast, dialysis patients within RDU were infrequently reviewed by medical staff, with a lack of serious engagement and no appreciation of patient priorities, leading to poor understanding of information or treatment choices. Patients who were 'difficult' or had multiple co-morbidities became side-lined. Specific problems existed with fistula access, anaemia, poor dialysis adequacy and nutrition. The interviews highlighted poor organisational support through sub-optimal policy guidelines and a resistance to change, with the RDU environment becoming increasingly impersonal. In particular, the rapid increase in patient numbers created immense pressure, compounded later by the necessary strategic responses to decentralise dialysis delivery through new satellite unit developments and the growth of Outreach Services.⁵⁰

In 2001 the NT Australian Labour Party won office from the long-standing incumbent Country Liberal Party. An ensuing strategic DHCS re-evaluation allowed mainstream national developments of home or community-based RRT to be more seriously discussed, alongside re-organisation of critical supportive renal services.⁵¹

1.2.2 The period before dialysis

As part of the preliminary, systematic investigation undertaken by WDNWPT, described on p.50 (and Appendix 2), WDNWPT retrospectively tracked the progress of all its' 27 members (4/01–4/04) along the pathway of care across service jurisdictions between bush and town described earlier. The intention was to describe the experience up to and including dialysis, to build a more complete picture for members and stakeholders.

1.2.2 a) A narrative of *Yanangu* resistance to intervention

Whilst reading medical files of WDNWPT members, it is impossible not to see the distress and communication difficulties being encountered by all involved in care, as the documented need for dialysis grows within an environment of crisis. Here is part of a PHCS referral letter concerning a 43 y.o. lady with ESKD:

11/97 *"She is adamant she doesn't want to move to Alice Springs (at this stage). She is not sure about finishing-up at (community name)".*⁵²

WDNWPT members often ‘refused’ or ‘declined’ investigation and dialysis preparation, several resisting hospitalisation or leaving care early, despite being unwell and aware of the implications of palliation. This next lady was first diagnosed with ESKD the month after her close relative died on dialysis in Alice Springs:

5/00 Renal OPD: dialysis education, reluctant for dialysis, for a/v fistula
6/00 Renal OPD: attempt fistula, “TOL” (Took Own Leave), undecided on treatment
7/00 Renal OPD: short of breath; refuses dialysis, a/v fistula
8/00 Renal OPD: “not keen on PD, unwilling to stay in A/S”⁵³

She was finally admitted for her first dialysis the following month, aged 43 yrs, from a ‘Sorry Camp’ in a remote community, this time mourning the death of her grand-daughter.

Sometimes services might ignore clear stated preferences, whilst the individual raised concerns of dislocation. Here, a 36 y.o. lady faces tremendous stress only 2 months before commencing dialysis:

2/97 Community PHCS RN: “Her preferred option is renal transplant”
3/97 Renal OPD: seen in Emergency Department short of breath, treated with diuretics. Apparently had been refusing treatment in (community name). “The main point of contention regarding her refusal to accept RRT is relocating from (community name) to A/S or even elsewhere & the subsequent fate of her children – three in number, the two elder ones are already petrol sniffers”.
4/97 Renal OPD: “I fear that in spite of our best efforts, she does not know what is good for her.”⁵⁴

She died 4 yrs later. Entries describe the anger accompanying this resistance. In this example, a 62 y.o. lady is struggling, strongly influenced by her prior experience:

11/02 I/P entry “Clearly (name) is v. angry re renal diagnosis. Is in denial. Clearly has been advised re fistula/diagnosis etc. + is angry/in denial”
3/03 I/P entry “doesn’t seem to accept diagnosis of CKD and it has been difficult to broach the subject She is familiar with RRT as her (close relative name) was maintained on HD, but he died in (date)”⁵⁵

She took just 9 months to progress from first diagnosis of kidney disease to reach dialysis, aged 63 yrs. Her close relative had died on dialysis 18 months earlier, following emergency evacuation from traditional ‘Sorry Camp’ grieving ceremonies for his recently-deceased daughter-in-law and grandchild.

It was beyond the WDNWPT investigation to present such non-Indigenous descriptions of routine *Yanangu* experience in a quantitative context as an index of service quality. The examples above weren’t collected systematically, however such descriptions are assuredly representative of the routine *Yanangu* resistance to service delivery focused upon shifting to town for treatment. They also fit into the descriptions of mutual poor communication and engagement described elsewhere,⁵⁶ and local practitioner experience. They are linked to grief and perpetuation of injury, themes taken-up in the ‘Bereavement’ process on p.48.

A contributing factor to WDNWPTs' difficulty in presenting an incomplete *Yanangu* description of the experience prior to dialysis, is that members on treatment found the subject too difficult to address at interview, often becoming uncomfortable as memories of personal hardship or family loss were invoked. There is no catharsis for *Yanangu* voicing such memories, and direct questioning was avoided by the WDNWPT interviewer, perceived as harmful or injurious. Here a reminder has inadvertently sharpened one participants' feelings of loneliness and hopelessness:

*“As I think about these things I don't know what to do. I go and lie down on the dialysis machine and afterwards rest for a day or so, then the following day they take me back again ... It is poor me, (name) who is talking and who is on dialysis.”*⁵⁷

The importance of such sensitivities was raised by one Governing Committee member, who chose to illustrate how *Yanangu* might need to be approached by health practitioners concerning chronic disease or dialysis. The abrupt, focussed modern medical consultation experience, and its harmful consequences of shame, worry and hence illness, is contrasted with a slower, gentler approach, more roundabout as though the individual were grieving:

*“It's like being sad. We don't like to tell someone – “Oh you are sick!” No, got to have it a little bit like hiding something, like a secret. You can't just tell anybody otherwise you'll hurt their feelings. You've got to keep it secret and tell them slow way, because there are lots of other *Yanangu* living with sickness. Yes, they become sick if you don't tell them like that. Like when the whitefella says, “Oh you are a sick one!” No, you should leave that sort of talk. Telling them like that can hurt their feeling, hurt their heart and make them worry and become ashamed. This is what people are thinking when they go to town and the doctor is looking after them, always asking questions, taking samples, doing things with machines. They should talk slowly and carefully. “I am trying to help” – kind way.”*^{58,59}

Positive approaches by themselves cannot be enough however, as what emerges must be dealt with, or formidable issues will be left to fester. Here is an example within one individuals' regional hospital files, when an new, non-Indigenous medical registrar organised the first documented assistance offered by an interpreter, in a consultation with a young WDNWPT member who was frequently hospitalised for missing dialysis:

2/8/98 “Noted 88 admissions prev., frequently overloaded; –accomm problems: -evicted for bills ++; Now living in creek, tent by choice; Lost cousin on dx, and her sister and her husband (bro-in-law) all in 5 days – withdrawn, uncommunicative. Young son and teenage daughter cared for by sister in WA. Alcoholic husband. Homesick.”⁶⁰

Despite reservations, some *Yanangu* took their regular attendance at Renal Outpatients in Alice Springs very seriously, despite great personal hardship coming to town up to fortnightly in some cases:

“... it was never ending, I never missed ... I remained there (hostel name) with out moving until sunset and still I stayed. They brought me food on a plate. I wasn't going anywhere. I stayed to avoid the drunks and those who hit you - those people who hit you when they're unsuccessful asking for money. I stayed until finally ready ... I wasn't lonely, I just stayed because I had to.” ⁶¹

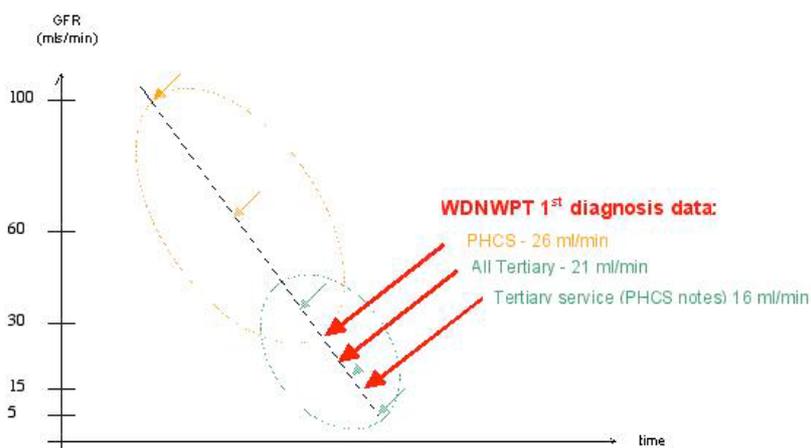
1.2.2 b) Quantitative investigation of the pre-dialysis period

Sections 1 and 2 in Appendix 4 detail quantitative results of the systematic investigation of the 'pathway of care'. Though the sample was relatively small, a number of serious concerns are raised, as summarised over the following sections:

i) Inattention and late diagnosis – not late presentation

WDNWPT members were diagnosed far too late by services (Fig. 5 below), already having established, moderate kidney failure, requiring active care from NT Renal Services and PHCS. This was not 'late presentation', files showed regular prior attendance, including referral and care of co-morbidities, with relevant assessment at all levels of care. At dialysis, 41% had proven or presumed diabetic kidney disease.

Fig. 5. First diagnosis of renal failure by services and GFR



Whilst PHCS showed inattention to early stages of kidney failure, tertiary services failed to communicate existing situations, either between clinical departments in hospital or back to PHCS, leading to multiple 're-diagnosis' and inaction.

ii) Lost opportunities due to fragmented specialist care

First diagnosis of kidney disease at the tertiary level was the final opportunity for a significant number (47%) of WDNWPT members to hear about RRT, or even to learn they actually had kidney failure. Being referred too late to a Specialist before dialysis ('Late Referral'–LR)⁶², is one national summary indicator of access to renal services, and is linked to poor outcomes.⁶³ WDNWPT LR was sub-optimal at 27% (NT 15%; national 23%). However, over 50% had no specialist care whatever in the final 5 months prior to starting dialysis. Effective tertiary system integration present a real challenge to the to support Renal Service intervention, alongside meaningful engagement with PHCS in the final months before dialysis.

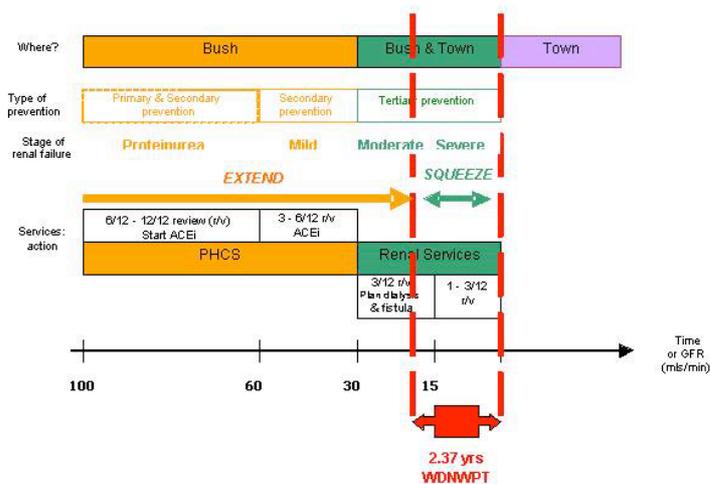
iii) Communicating staging of kidney failure

There is insufficient basic calculation of GFR to identify then communicate the stage of kidney failure to co-ordinate intervention. Recent developments may well assist this, through routine laboratory reporting of calculated GFRs, or promotion of web-based calculators,⁶⁴ however the risk is that all services will simply plot *Yanangu* demise more accurately.

iv) The squeezing of NT Renal Service opportunities

60% of WDNWPT members took 2 years or less to reach dialysis following their late diagnosis. This brief period of rapid deterioration might be described as 'untreated' in consideration of the evidence from Fig. 3 (p.17) showing a similar loss of 20 mls of kidney function in just over 2 years.⁶⁵ Fig. 6 below illustrates the resultant squeeze upon time.

Fig. 6. Squeezing the opportunities for NT Renal Services intervention



1.2.2 c) Consequences of lost time and opportunities

Ultimately this compression has three important consequences upon the attempts to engage individuals as *Yanangu* begin to react to the situation:

i) Reduces *Yanangu* opportunities for fistula (access) preparation

Only 19% of WDNWPT members received a fistula more than 6 months prior to starting dialysis, the period required by accepted national guidelines.⁶⁶

ii) Promotes arrival into the dialysis system in crisis

Rather than a smooth transition onto dialysis, 87% failed to be managed electively, spending an average of 3 weeks overall in hospital with 1 in 5 entering Intensive Care (ICU). Of the 3 individuals who were managed electively, 2 went on to receive transplants. As the only WDNWPT members to receive this RRT, this strongly suggests more powerful downstream effects of good management during transition onto dialysis.

iii) Limits opportunities for *Yanangu* to receive good RRT information

To discuss RRT implications requires sustained, cross-cultural engagement between individuals, families and health services at home. *Yanangu* persistently say that meaningful opportunities must be available on communities, and can't be simply met by concentrated periods offered in town. Patients need more time to involve families, with time to consider housing, schooling, work and the myriad details of changing a life should dialysis be necessary. Sensibly, such a context would lie within PHCS chronic disease management, especially type-2 diabetes and hypertension, where individual risk of going to town, possibly to live could be part of any discussion. PHCS are best-placed to offer accurate information over time, including dialysis and transplant, but have reasonable concerns about extra workload, lack of educational resources, the challenges of unfamiliar technologies and the different emphases in prevention. However, an equal role in developing integrated programs supporting both PHCS and Renal Service strategic direction, alongside extra dedicated funding, would support the necessary individual engagement and regional co-ordination required to seriously address the current situation. In effect RRT would become one of several appropriate chronic disease treatment modalities.

As individuals went onto dialysis, there were no referral letters from remote to town-based PHCS concerning future care, of particular concern given the high level of co-morbidities, whilst only 13% of files recorded the date of starting dialysis. *Yanangu* disappear from the PHCS view, with RDU becoming responsible for all complex, 'holistic' health needs from this point.

1.2.3 On reaching dialysis

i) Highest dialysis prevalence

Within a region already enduring some of the nations' worst kidney health statistics, WDNWPT communities appear as a 'hot spot' of need. With an Indigenous population of around 2500 (12% of the region),⁶⁷ there are 6200 pmp (per million population) on dialysis (mean prevalence), as opposed to NT (1225); national Indigenous (1717); Kimberley (1745)⁶⁸ national (386).⁶⁹

ii) Limited RRT choices

The national picture of dialysis choice is dynamic, with around 30% of home treatment done at, (2:1, PD:HD). All WDNWPT members received institutional HD by default within RDU until 2001, the most expensive RRT option,⁷⁰ requiring families, carers and patients to live permanently in town, with 100% arriving from remote locations (RDU 75% overall; Darwin 51%).⁷¹

iii) A crucial segment of the community removed, permanently

WDNWPT members were predominantly female, starting dialysis significantly younger than *Yanangu* men (mean 42.9 vs 53.7 yrs), roughly a decade younger than their national counterparts. During the investigation period 41% (n=11) passed away. They survived an average of 2.5 yrs on dialysis, at least as poorly as other Indigenous patients on dialysis in RDU, who all survive for shorter periods than the national non-Indigenous population. The NT is in line with national RRT mortality rates, with about one quarter of dialysis patients dying each year, with estimated survival less than that for breast cancer. Most non-Indigenous people, including health service staff and management, don't appreciate that survival on dialysis is routinely poor. One WDNWPT member said,

*"Family members who stay too long in town are dying, one after the other they all die"*⁷².

1.2.4 Summary

The retrospective investigation by WDNWPT implies there is a challenge for all services and fundholders to share responsibility to reduce the gradient of GFR deterioration – to delay or prevent CKD progression. In identifying their possible interventions, each needs to expand the time and opportunities available to afford sustained discussion out bush of RRT, whilst linking into a coordinated framework that emphasises long-term community-based solutions over expensive institutional HD in Alice Springs. There is a significant contribution to the more widely accepted reasons for 'poor Indigenous dialysis outcomes', of a lack of integrated services and functional quality. This lack of critical, effective mass has created a persistent gap

between what's actually happening on the ground and policy, whatever the strategic intent. The poor outcomes are exacerbated by jurisdictional division and well-intentioned programs mounted in response, which fail to address expressed *Yanangu* needs as to how to maintain well-being, being described as harmful by these consumers. Individuals and communities are affected in turn, and outcomes currently may be measured by late diagnosis, poor engagement at individual consultations and communication between services, inadequate preparedness and entry onto dialysis in a critical condition, with ultimately poor survival time and quality of life. Furthermore, WDNWPT will show later that this legacy affects attendance at routine dialysis and associated hospitalisation, alongside significant social effects upon the regional communities as *Yanangu* are obliged to live in Alice Springs permanently, treated within RDU, the largest single dialysis complex in the Southern Hemisphere.⁷³

1.3 WDNWPT development through '*Yanangu Way*' & '*WDNWPT Way*'

In the face of this litany of hardship, *Yanangu* raised money to meet their own needs and aspirations. WDNWPT was developed as a vehicle to achieve these, and its' development is best appreciated through understanding two, complimentary processes at work. Underpinning everything are fundamental *Yanangu* identity and process – '*Yanangu Way*'. In turn these are operationalised and expressed by WDNWPT, an organisation with a notion of this appropriate process and relationships – '*WDNWPT Way*'. Without the reader yet being aware of WDNWPTs' specific structural development, at this point in the narrative it is important to begin to address '*Yanangu Way*', and its' role as the prime-mover of all things WDNWPT.

1.3.1 '*Yanangu Way*'

Since its' inception, a *Yanangu* Governing Committee, comprising 10–15 senior regional community members have been at the core of WDNWPT activities. At interviews conducted by WDNWPT during a systematic investigation of its' activities, members of the Governing Committee spoke of their place in articulating the continuity of *Yanangu* ideas and work within their communities, and the advocacy by particular individuals in the past, especially Smithy Zimran Tjampitjinpa (1958–2001), who declared prevailing *Yanangu* concepts of identity as linked through home or country (*ngurra*), family or relatedness (*walytja*), and culture through Dreaming (*tjukurrpa*), songs and ceremonies (*tulku*).⁷⁴ As *Yanangu*, statesman, *Ingkata* (pastor), and later as a dialysis patient, Zimran also shared the experiences of WDNWPT members.

“... Smithy Zimran could speak strong English to newspapers and government people, but he had the same idea, which he always held, because he had a skin name⁷⁵ and a family group, and he always showed concern, sorrow for others.”⁷⁶

The Governing Committee and members on dialysis remind us that they too share this same *Yanangu* identity:

“He died and is no longer with us, but we still speak of him. We will be mentioning it still, because he always spoke strong for all Pintupi. He didn’t talk only for one person, for himself, but for all his friends and family. For everybody, all his family, those from Tjukula, Kiwirrkurra, Kintore, Nyirrpi, Amunturrngu, Papunya, Haasts Bluff. He always spoke for all Yanangu.”⁷⁷

Similarly, the Governing Committee – his family (*walytja*), continue to carry this responsibility:

“All of us have always thought like him, you know. And today we always talk the same way as he did, keeping on strong for others and for those who’ll come behind.”⁷⁸

Through this shared identity of *Yanangu* belonging, of skin name, of participation at ceremonies, grows respect for family and kin. Demonstrating concern or compassion (*kuunyi*; *alturringu*), showing generosity and reciprocity (*ngaparrtji-ngaparrtji*) for those in need (*kuunyi*; *ngaltutjarra*)⁷⁹ – shows respect, a part of being human and definitely part of being *Yanangu*. WDNWPT members feel they need to remind onlookers that they are human beings like everyone, and that *Yanangu* on dialysis in Alice Springs, and their families currently live ‘in need’ and deserve compassion. It is *Yanangu* who best understand this (*kulintjaku*), knowing (*nintintjaku*) how they need to live as *Yanangu*, especially in maintaining their own well-being.

Becoming *Yanangu* through learning, knowing and understanding, can’t be done passively by merely hearing or even listening, they require action (*palyantjaku*) and practice (*palyani*) as life-long processes. When *Yanangu* identity is whole, happiness (*pukulpa*; *yunyparringu*) and contentment (*walykamunu*) grow. Through active engagement they become strong (*kunpurringu*) and are given more life (*kanarringu*; *wanka*), as their spirit (*kurrunpa*) becomes well (*palya*; *wiru*). This is how *Yanangu* wish to live, maintaining their own well-being.

All this is in sharp contrast to the earlier descriptions of ‘dislocation’, the cumulative *Yanangu* experience of living in Alice Springs on dialysis. Shame (*kunta*), loneliness, despondency and depression (*tjituru tjituru*; *tjiluru*; *watjilpa*) affect individuals, family **and** country **and** Dreaming alike. In turn, these then diminish *Yanangu* health and well-being (*kuyarringu*; *kurrarringu*), whereby *Yanangu* may become sick (*pikatjarra*, *miintarringu*) or pass away (*wiyarringu*) much earlier than they might.

*“They can’t leave their country. They think about their spirit and they think about their Dreaming, land and country. They can’t leave their families. Culture is the main one. They can’t leave the place where they were born. They want to stay because they have grown up in that country. Their land is what they think about, because if they go to another place they get sick and weak. Doing that they lose the spirit in their heart, and that is why they need to stay home.”*⁸⁰

‘*Yanangu Way*’ offers an explanation as to why ‘dislocation’ is so disastrous. It also shows where *Yanangu* see the solutions, and how determined they are to achieve successful outcomes. The description here also demonstrates a holistic perspective of health, emphasising the need to have control. Smithy Zimran once more illuminates this:

*“The (Yanangu) law is like a human being, it works with Aboriginal people – Yanangu. Yanangu and the law is together. If that law is weakened, people get weakened and they feel they are weak because they have taken away power in the community. That is the whole issue about community control under Aboriginal law.”*⁸¹

All WDNWPT activity attempts to meet these *Yanangu* expressions of well-being. ‘*Yanangu Way*’ is existing Indigenous capacity, so often portrayed as deficient and linked with the requirement for ‘capacity building’. The real challenge is for stakeholders, particularly government, to address their own capacity needs to meet and work with those of a different world-view.

1.3.2 ‘WDNWPT Way’

‘*WDNWPT Way*’ describes the sustained attention displayed by the organisation to operationalise ‘*Yanangu Way*’ at all levels of its’ function. Expressed *Yanangu* needs are met through developing appropriate reciprocal relationships, services and governance. Appendix 2 gives a lengthy description of initial groundwork laid during 4/01–6/03, required to establish WDNWPT as a relevant regional player. It provides a ‘close-up’ description, an immediate flavour of the community development approach which continues today.⁸² Fundamental are *Yanangu* engagement in planning, decision-making, action and reflection across individuals, families and communities. Appendix 2 also outlines the non-Indigenous WDNWPT workforce development, and underscores the important contribution financial independence still makes in facilitating careful community consultation and nurturing governance development.

1.3.2 a) Characteristics of ‘WDNWPT Way’

‘WDNWPT Way’ has several singular characteristics, some of which are shared with NGOs in contrast to government or more specifically health bureaucracies:

i) Sustained governance

A significant recurrent financial investment is required to engage *Yanangu* remote consumers from across the region, to meet, articulate *Yanangu* issues, consider complex non-Indigenous health contexts then build effective responses. Currently WDNWPT spends \$35,000/yr on 3–4 major meetings of the Governing Committee.

ii) Remaining accountable to *Yanangu* consumers

WDNWPT emphasises accountability to *Yanangu* through its’ relationships, whilst maintaining those due external agencies, including Registrar of Aboriginal Corporation and funding providers, creating difficulties across different timeframes and accountability structures. WDNWPT accountability is viewed through *Yanangu* expressions of well-being and the intimate relationships between members achieved through consultation, planning, consensus and advocacy. It also recognises *Yanangu* requirements to institute service delivery alongside development. Specifically, ‘Patient Meetings’ are held in Alice Springs every 4 – 6 months, to provide and develop transparent consumer accountability and advocacy.⁸³

iii) Credible advocates

Remote *Yanangu* communities recognise WDNWPT legitimacy and credibility through kinship, identity and shared experience. Identified needs are addressed through persistence, consensus and a respectful process, despite local community upheaval and institutional change. This acknowledges Governing Committee direction that stresses secure, non-coercive relationships. There is a constant need to minimise tensions that arise in accepting *Yanangu* priorities, especially those which test non-Indigenous professional or bureaucratic boundaries. On occasion, funded resources such as information or workforce can be committed, not just ‘in-kind’, to support the development of such relationships. There is an appreciation of the chronic ill-health of most members, and the toll such advocacy takes.

iv) Services and workforce

The flexible services aimed specifically at maintaining *Yanangu* well-being, have an objective of synergistically supporting existing mainstream services where possible. They are described by *Yanangu* as culturally-secure. The committed, credible workforce prioritises relationships with *Yanangu* to develop shared notions of need, compassion, responsibility and harm. They bring relevant experience and flexible approaches to the dynamic context of relationships within WDNWPT, including members with aggressive illness. This commitment flows through to attempts to sustain important positive stakeholder relationships, especially with RDU, in recognition that a) care of members on dialysis must not be jeopardised, and b) such relationships are based on cultural values of reciprocity.

v) Investment in relationship networks

Crucial to the consultation process and delivery of services has been the significant investment made to develop and maintain key local and regional relationships with individuals and institutions that support change. Using local organisations to provide brokerage, formal partnership arrangements have been offered through MOUs, intended to strengthen service delivery. Working in an uncertain funding environment, concepts of mixed government and philanthropic funding have been pursued. These are strongly influenced by bureaucratic and health professional perceptions of ‘need’ or ‘evidence’, alongside the vagaries of political context. Excepting philanthropy, all have a debilitating submission timelag and accountability structure attached.

As part of WDNWPT monitoring activities, key Indigenous and non-Indigenous stakeholders were interviewed about the organisations’ advocacy model. The Governing Committee members spoke of the personal struggle they endure. Marlene Nampitjinpa⁸⁴ describes the visit by M. Wooldridge, then Federal Minister of Health, who laughingly dismissed the notion of Commonwealth support for dialysis at Kintore:⁸⁵

“Yes, he told us he couldn’t help this place here at Kintore. We still kept on fighting, intending to get a machine placed here in our homelands at Kintore, for our people, for our people who have to go such a long way away. We pushed our government hard,⁸⁶ trying to make them give help to Kintore, they did not. We kept talking for a long time.”⁸⁷

They described the personal toll activism had upon them, some retiring due to ill-health. Most had family members on dialysis, alive or deceased, and whilst being explicit that situations should be approached calmly, there were clear frustrations in trying to make the grinding

inertia of non-Indigenous government forces understand and act, whilst being daily reminded that their relatives were growing sicker and dying.

“We really lived upset, really sad due to all the Yanangu who became sick, all those early ones who belonged to all of us. All of these people of ours died for no good reason, too early in life. They were living happy having come to Kintore (from Papunya),⁸⁸ then after they shifted to town some family died. In the beginning we were always really sad, losing all our family. Their machine was built behind them (ie too late), all those poor people. For a long time we always talked, always talked, always talked and finally got this machine. (WDNWPT) helped us having heard and understood.”⁸⁹

A second part of Nampitjinpa’s repost above outlined the non-Yanangu contribution from WDNWPT employees:

“We have got our helpers always standing by us, always understanding, (WDNWPT staff names). Because of this they are ours, always helping. They give us Aboriginal people information and push our stories (decisions). These many white fellows, they belong to us, living with us, they’re always working, always helping us. Having written down our story, they send it away, always helping, (WDNWPT staff names).”⁹⁰

The use of terms such as: *helpers; always standing by; ours; understanding; belonging to us; living with us*’ suggest a culturally-secure, respectful relationship.

1.3.2 b) Non-Indigenous views of WDNWPT

Non-Indigenous participants⁹¹ described WDNWPT as having a broad and powerful impetus at a number of levels to drive change in renal health service delivery to improve quality of care. They highlighted:

i) Fundamental community role

The value of the community focus as a starting point to suggest there might be more than one way to deliver integrated community-based services, so as complex micro- and macro-level issues could be addressed to inform disparate groups, including WDNWPT itself alongside NT Renal Services.

ii) Sustained project coordination

A key ingredient identified was the presence of a long-term Coordinator working with the Governing Committee, then assisting institutions in turn.

iii) Non-adversarial advocacy

Overall, the (mostly) non-adversarial process nurtured relationships that identified common goals and minimised boundaries, both at the personal, team and institutional level.

iv) Positive RDU relations

The relationship with RDU was particularly appreciated, where WDNWPT intent to support positive experiences for staff were seen as flowing on to patients as well. Not everything was easy however, such relationships are being particularly tested by the ‘Bereavement’ process (see p48), with an appreciation that this is ‘unfinished business’ for everyone.

The overall impression was that the WDNWPT process motivated a fulfilling life outside dialysis for its’ members, with an improved control over the daily struggle.

“You’ve all done a pretty bloody good job. You know, when you think that not only are you working with a particularly isolated and difficult region, which then lends itself to isolated and somewhat difficult people, (laughter) it’s been good, it’s been a pretty good outcome really.”⁹²

1.3.2 c) Comparison with other relevant advocacy models

In addition, one nephrologist⁹³ specifically contrasted the WDNWPT advocacy model with other contemporary examples of regional Indigenous advocacy in community-based dialysis:

- i) patient-based advocacy was generally unsuccessful. Individuals on dialysis have high medical commitments, and are frequently distracted by illness and the effects of dislocation, draining the sustained political, intellectual and emotional investment required
- ii) extended struggles may mean important individuals on dialysis die prior to the conclusion
- iii) senior individuals with good local and particularly federal political connections can be successful. However resulting satellite-based models are inevitably not placed in all client communities, so dislocation effects, transport, and high service provision costs can remain
- iv) remote community advocacy can become distracted by important, consuming local issues
- v) sustaining integrated advocacy over time can be problematical within community organisations, exacerbated by workforce turnover, so that movement through inevitable barriers encounters further delay, frustration and a lack of pressure
- vi) poorly-informed or naked political ambition can result in crucial regional stakeholders being excluded from processes. Quality patient care requires coordinated, sustained patient management between a variety of services, and the detrimental ramifications of ‘exclusive’ processes may remain long after the ‘bricks & mortar’ of a dialysis unit are in place

Summarising WDNWPT, he concluded:

*“Advocacy at the community level to move through those issues has been very important, because I think unlike those other experiences, there is likely to be ... a more sustainable and successful model, both financially & logistically in the long-term with that more flexible approach.”*⁹⁴

Shared *Yanangu* identity and determination set priorities to institute services that meet their own needs. Such identity embraces many cultural-specific determinants which focus on a life-long requirement to nurture family, country, Law and Dreaming. Any processes that diminish these are harmful, those that embrace them, such as *WDNWPT Way* sustain *Yanangu* well-being. The next section examines the particular services WDNWPT has put in place, and an investigation of their effects.

2. WDNWPT solutions

Earlier descriptions of ‘*Yanangu Way*’, ‘*WDNWPT Way*’ and ‘*Dislocation*’ underpin the solutions WDNWPT have put in place, falling into three broad areas described below:

- 2.1 ‘Lifelines’: providing immediate support to dislocated members on dialysis in Alice Springs, including (2.1.1) ‘*Yanangu advocacy malpa*’ (‘*YAM*’); (2.1.2) ‘*Return to Country*’
- 2.2 Long-term developments: changing dialysis delivery context, including (2.2.1) ‘*Going Home*’ and (2.2.2) ‘*Bereavement*’
- 2.3 Monitoring activities: describing the quality of services to members and stakeholders

2.1 ‘Lifelines’

2.1.1 ‘*Yanangu advocacy malpa*’ (‘*YAM*’)

‘*YAM*’ arose from family desire out bush to demonstrate their concern and compassion (*alturringu*) for relatives away on dialysis Alice Springs. The Pintupi word *malpa* describes a companion sharing experience, rather more than simply ‘a friend’. The need for an employee based in Alice Springs to carry the service arose from the earliest WDNWPT development discussions, and was confirmed then instituted following the 6-month scoping work in late 2001 by J. Hulcombe for the Governing Committee (see Appendix 2). This identified a need to provide a responsive service that supported developing informed choices in a wide variety of contexts, including personal, clinical and social.

2.1.1 a) Initial program development

First known as ‘Patient Support’, J. Wurst was employed part-time (24 hrs/week) to focus upon advocacy with members and families, engaging a multiplicity of local institutions, cultural and social networks, or welfare systems necessary for survival, including RDU.⁹⁵ Aiming to balance strategic initiatives to improve quality of life, whilst responding to individual requests supporting the ‘family on dialysis’, both required close liaison with the new Manager position (S. Brown).

Several activities, highly-valued by *Yanangu*, were developed during this initial 2-yr phase, best summarised as ‘assistance to engage’ with numerous medical institutions, cultural and social networks or welfare systems:⁹⁶

- regular patient and family ‘singalongs’ grew into the ‘Western Desert Renal Choir’, a focus of great pride for members and RDU staff alike, offering spiritual and social opportunity to participants. Performance locations vary from local institutions (Old Timers Home) to public (Alice Festival, CRCAH Convocation and Desert Sound)
- outings such as picnics, short bush and town trips, provided by employee personal transport
- helping *Yanangu* settle into houses, reporting faults, checking agreements
- accompanying *Yanangu* when they feel vulnerable eg RRT negotiations with hospital staff
- official hospital visits; supporting staff, including RDU, to consider *Yanangu* perspectives
- assisting members to maintain contact with each other during their frequent hospitalisations
- local Memorial Services for members who pass away, attended by patients and all staff as a way of ‘finishing up’ (see ‘Bereavement’ p.48)

2.1.1 b) Evolution of ‘YAM’

After J. Wurst retired (12/04), her position was filled by A. Lynch and G. Stewart (each 16 hrs/week) in response to an increasing workload, with more WDNWPT clients and the shift of ‘Return to Country’ administration from RDU Social Work to WDNWPT. In addition, the RDU position has been vacant three times in the last 12 months, and increasingly WDNWPT is called upon to take-up basic services traditionally delivered by that department. The new WDNWPT staff came with valuable complimentary skills and pre-existing *Yanangu* relationships. With a front-line response to early intervention and support, alongside strengthening WDNWPT advocacy, their roles now focus on reversing the routine disengagement from town-based support entitlements experienced by members, particularly early on in ‘transition’ to town. Current cost \$70,000/yr., (plus \$20,000 Emergency Relief; \$10,000 km allowance)

2.1.1 c) Key ‘YAM’ activity areas ⁹⁷

- i) Accommodation:** Supporting *Yanangu* housing applications, pre-tenancy interviews, establishment and maintenance of public housing; procuring furniture, blankets and household goods to support healthy living; assisting hostel placement negotiations.
- ii) Financial:** Ensuring entitled access to Carer Respite Resources, Centrelink work payments, Frail Aged & Disable services and transport subsidies, occasional emergency relief.
- iii) Clinical care:** Accompanying *Yanangu* to medical and diagnostic appointments; increasing access to traditional healers (*ngangkari*); gaining access to established physiotherapy and Occupational Therapy services; attending weekly multidisciplinary ‘Traffic’ meetings at RDU to ensure good communication between WDNWPT and the Social Work department.
- iv) Supporting WDNWPT programs:** Assisting to prepare members and stakeholders for ‘*Going Home*’; assisting with ‘*Return to Country*’ coordination; emergency relief provision (food, clothes, shoes, temporary accommodation, blankets). Check-lists and pictorial models describing the integrated ‘YAM’ activities are important developments here.
- v) Early intervention:** the development of close relationships and monitoring of social situations has encouraged members to come forward and identify looming issues.
- vi) Advocacy:** Organising and running ‘Patient Meetings’ to provide an active consumer voice for WDNWPT members on dialysis, where a confidential forum for members can hear concerns, particularly accommodation, cultural security of dialysis services and transport around town. Strengthening such local networks through participating in CARSWAG,⁹⁸ Accommodation Action Group and similar forums where WDNWPT priorities are raised. Mediation between institutions and members is frequently required.
- vii) Life outside dialysis:** Social outings such as bush tucker trips, carers trips, and the regular popular days to the Alice Springs Desert Wildlife Park provide further opportunities for members on varying dialysis schedules and living in different locations, a chance to spend time together around activities unrelated to ill-health!

More recently WDNWPT became registered with Australian Volunteers and Alice Springs Town Council (6/05). Two long-term volunteers now support very different approaches to members on dialysis, a “Scooter Program” facilitating mechanised access to the Alice Springs Desert Park and outings; the other offering massages. WDNWPT pays the \$1000/yr for relevant insurance, and is seeking further linkages to the broader Alice Springs community. The effectiveness of ‘YAM’ is greatly enhanced by contributing roles of Manager and Community Development (S. Brown and J. Hulcombe). Beyond their regular contribution

when the two part-time ‘YAM’ workers are not available, they link the local issues and decisions of members on dialysis to families out bush via the informal and formal WDNWPT governance processes, alongside relevant action, including lobbying and publicity. Broadly-speaking the strengthening of *Yanangu* networks is taken by JH, whilst SB addresses the substantive stakeholders issues, together costing around \$40,000/yr as WDNWPT ‘in-kind’.

2.1.1 d) Discussion

Yanangu aren’t passive in the face of the considerable difficulties surrounding dialysis delivery. Families out bush meet their own obligations and responsibilities by funding ‘YAM’, stressing the mutual benefit to the well-being of the broad family or community affected by dialysis. Similarly, a ‘family on dialysis’ exists in Alice Springs, members giving friendship within hostels and supporting each other through the relentless cycle of hospitalisation and ‘treatment’. The development of regular ‘Patient Meetings’ links *Yanangu* consumer concern, advocacy to action via ‘YAM’ workers and management as part of ‘WDNWPT Way’. Accommodation remains a critical issue for all dialysis patients in town, both shortages and appropriateness. Reversing an earlier trend, most members have now left Town Camps seeking other options, citing a climate of fear and abuse, theft (especially of food) and poor living conditions. The table below summarises local issues:

Table 1. Accommodation for WDNWPT members (at 12/05)

Option (no.)	issues
Anglicare Lodge (1) Ab. Hostels (16) Church Hostel (2)	>\$20/night + meals, leaves \$60/wk in hand approx. Increasing climate of reluctance to take on difficult, highly dependent, long-term “Renals”. Delay to hostel construction exacerbating tension.
Public Housing (3)	Intensive support required (\$ and time). Cultures of neighbourly complaint and officious scrutiny, alongside extreme difficulties caused by visitors make this desirable area fraught.
Motel (2)	\$500/wk, members are caught in debt cycles involving painting canvases for shelter. WDNWPT provides emergency relief
Town Camp (2)	Satisfactory for permanent residents with recognised connections to the areas. Arduous for those regarded as visitors.

Despite positive steps, WDNWPT continues to stress the belief that ongoing harm is being experienced by *Yanangu*, as suggested by the excessive numbers from the WDNWPT region requiring dialysis and the destitution expressed by those dislocated in town. This group is characterised by high levels of recurrent illness, depression, homelessness and poor self-esteem leaving them vulnerable and open to exploitation, and poorly-equipped to take advantage of over-stretched mainstream services. WDNWPT finds itself in a cleft-stick as to achieving a reasonable balance between ‘YAM’ and taking-up government areas of service responsibility.

A single RDU Social Worker position is unable to provide a meaningful spread of patient support beyond a bare minimum for *Yanangu* members entering the dialysis system in crisis. Quite reasonably RDU staff select WDNWPT 'YAM' services as the entity most likely to meet their own and client needs. There is no service duplication, at best it is synergistic, whilst there is a reasonable argument that WDNWPT is providing care that ought to be delivered by a larger, better-supported RDU work-force. WDNWPT has always considered the strengthening of existing service delivery alongside advocacy to be the first step. The challenge here for government is to support 'YAM' in a manner that doesn't compel it to become a simulacrum of mainstream service, whilst considering the important implications for other Indigenous clients and stakeholders.

If '*Yanangu advocacy malpa*' can broadly be described as an attempt to take the sharp edges off life in Alice Springs by providing positive opportunities for informed, individual choice, then '*Return to Country*', described in the following section, is a 'Lifeline' program aimed squarely at reinvigorating fundamental family networks.

2.1.2 '*Return to Country*'

Prior to WDNWPT, Smithy Zimran had summarised *Yanangu* need for suitable transport to be made available, so patients on dialysis could return for visits safely. Throughout the documented WDNWPT discussions of well-being summarised in '*Yanangu Way*' (see p.26), *Yanangu* emphasised that to remain healthy, all family members must sustain fundamental relationships with *ngurra*, *walytja* and *tjukurrpa*. Alongside simple visits, there is a need to be present for funerals, a major opportunity for both renewing acquaintances, being with family and ensuring that vexed issues arising from ritual 'Sorry Business' are handled appropriately. Nearly all WDNWPT members on dialysis are recipients of Disability Pensions (\$408–489/fortnight), and trips home are an expensive proposition, with return mail-plane journeys to Kintore currently costing \$630. In addition, great concern has been shown by all health services at the difficulties raised when dialysis patients return unannounced to remote clinics, having missed routine dialysis by overstaying home visits.

2.1.2 a) Program description

WDNWPT provides 6 free, return trips to home communities, coordinated between routine dialysis schedules at RDU. Often in groups, members visit home for short periods of time, equivalent to long weekends.

Appendix 5 presents a detailed activity data (4/01–4/05) with relevant cost comparisons.

2.1.2 b) Summary of activity

Whilst technically the program has been running since 4/01, real activity began in earnest from mid-2002. On average, each year 78% of WDNWPT members on dialysis utilise the service, making 5.3 visits each across 10 remote communities within the cross-border region.

Table 2. Cost of ‘Return to Country’ transport (4/01–4/05)

	% of members carried (av.)	\$ cost/visit (av.)	% of total annual cost (av.)	total \$ cost (av.)
vehicle	40%	\$218	24%	\$6508
plane	60%	\$463	76%	\$20,211
Overall	- av. cost/visit		\$378	
	- av. cost/person/year		\$1908	
	- av. cost/person month on dialysis		\$179	

Travel by planes formed 76% of the total cost. WDNWPT noted the importance of vigilance and coordination required to keep a lid on this particular cost area, especially with recent aviation fuel price increases. The observation has been made by WDNWPT staff that ‘Return to Country’ visits might be particularly important in the early period following commencing dialysis, as *Yanangu* try to set recent chaotic events into some kind of sustainable perspective. Over the last 12 months, 50% of visits by car now use private vehicles, supported by the use of fuel vouchers, comprising around 55% of total vehicle journey costs. This development seems a particularly cost-effective way to assist those on dialysis who have decided to continue to live on nearby home communities to Alice Springs (Ikuntji, Hermannsburg, Santa Teresa), and travel to town 3 times/week. Currently they are compelled to be dependent on relatives or supportive PHCS for transport assistance. In contrast however, the much longer dirt road to Kintore (travel time 6–7 hrs) is arduous, and so far marked by the crosses of three individuals killed returning from visiting relatives on dialysis. WDNWPT estimates the total cost of ‘Return to Country’ for all its’ members now at around \$50,000/yr, including coordination.

2.1.2 c) Discussion

To reinvigorate family relationships meaningfully takes more than long weekends at home. However ‘Return to Country’ offers *Yanangu* opportunities at their behest, to participate in and strengthen the kinship networks necessary for individual and community benefit.

*“Yuwa palya, it (WDNWPT) helps us to go back, especially when we have to find out how to go to Sorry Business, when we try to get lifts. Only the Western Desert is helping us wherever we want to go. Yea they’re helping us to go back for funerals and Sorry Business. The Western Desert – they’re working really well.”*⁹⁹

Ceremonial events such as those associated with funerals seem particularly suited to such a flexible, patient-directed program. The contrast with the situation existing before ‘Return to Country’ services were in place was typically summarised:

*“You couldn’t do it before, it’s only happening now. It’s only now that people can go ... All my family have heard about this and they’re excited. It’s good like this.”*¹⁰⁰

Part of *Yanangu* association with death and grief includes the necessary resolution of causation, responsibility through a ritual stressing relatedness, “... *an affair of the whole society.*”¹⁰¹

Absence can be interpreted by onlookers in many, different ways. ‘Unfinished business’ is particularly detrimental to those living and dying away from home on dialysis in Alice Springs (see ‘Bereavement’ p.48).

2.1.2 d) Systematic investigation of ‘Lifeline’ activities

In WDNWPT interviews, the anguish, depression, loss of spirit and hopelessness experienced by members on dialysis in town are placed in stark contrast with the pleasure, vitality and good health derived from being with family, especially at home. The increasing optimism and engagement with treatment displayed by WDNWPT members is covered in more detail on p.43 as part of discussions of the lengthier stays associated with ‘Going Home’.

As part of the systematic monitoring activities undertaken by WDNWPT, it scrutinised four important areas where measurable outcomes might be quantified – the emergency evacuations from remote communities required when patients missed dialysis when overstaying trips, routine dialysis attendance, missed dialysis and associated hospitalisations, and possible economic cost-savings. Results are summarised and detailed in Appendix 4, and show:

- i) Improved attendance by WDNWPT members at routine dialysis in RDU, now significantly better than all others on dialysis, who attend as before (3.1; Appendix 4)
- ii) A significant reduction in RFDS emergency evacuations from remote communities, despite increasing numbers of WDNWPT members and visits (3.2.1; Appendix 4)

iii) A significant reduction in WDNWPT member rates of hospital days and hospitalisation as a result of patients missing dialysis treatments, whether requiring acute dialysis or not. (3.2.2; Appendix 4). Similarly, a reduction was seen in the routine referrals from RDU to ASH for missed dialysis (*ibid*)

iv) Significant cost-savings. The overall cost/person month of acute hospital care declined from \$373 to \$268 (crude estimated savings of \$61,000). Real RFDS evacuation savings of \$52,000, estimated as \$111,000 despite increasing numbers of members. (3.3 ii); Appendix 4)

Further effects upon overall hospitalisation and dialysis quality require more work, but are nonetheless provocative (3.4 & 4; Appendix 4)

2.1.2 e) Implications of ‘Lifeline

Yanangu are quite clear that the health-benefits arising from ‘Lifeline’ programs meet their own criteria for addressing well-being. The real challenge for WDNWPT negotiations with government, has been to describe apparently idiosyncratic, overlapping activities as they develop, monitor, then link outcomes directly to discreet initiatives, whilst simultaneously meeting members’ demands to deliver urgently-needed services. The major interest from most onlookers has been to see *Yanangu* dialyse for the first time out bush, as described in the following section ‘*Going Home*’. However, the major impact thus far upon members on dialysis in town appears to have been delivered through the less sexy ‘Lifeline’ programs – ‘*Yanangu advocacy malpa*’ (‘*YAM*’) and ‘*Return to Country*’, which have been growing throughout WDNWPT development. The symmetry between the timing of the expansion of ‘*Return to Country*’ delivery and outcomes, especially routine attendance, suggest this program has made the major contribution to outcomes as presented. However it is part of a whole model of broad delivery, and the improved engagement, relationships with health services and impact upon communities all play their part.

The hospital data collected by WDNWPT is associated with acute or missed dialysis, and doesn’t assess the possible effects upon the major expense area of hospitalisation associated with co-morbidities. It would not be unreasonable to expect a cost reduction across the board due to the improved participation in routine dialysis, and would be possible to collect DRG data and examine the structure of hospital admissions in the future to provide a broader picture of the impact upon hospitalisation.

Regional plans aim to deliver holistic dialysis services at an acceptable quality to consumers and other stakeholders.¹⁰² WDNWPT makes the case that ‘good dialysis’, even when delivered within an institution, ought to be more strongly-influenced by consumer notions of well-being

and engagement. Through their own efforts, *Yanangu* have debated issues, set their agenda, drawn-up and delivered 'YAM' and 'Return to Country' programs, including the development of a consumer forum, linked to action and not simply talk. Thereafter they undertook investigation, which though preliminary, has shown positive qualitative and quantitative outcomes across communities and disciplines. None of this would have occurred without *Yanangu* having their own money and control over the process, however there is opportunity for funding groups now to consider new options to assist individuals and the broader community.

2.2 Longterm developments

The two long-term WDNWPT developments described in the following sections (2.2.1 'Going Home'; 2.2.2 'Bereavement') are further attempts to change the way in which dialysis delivery can address *Yanangu* needs of sustaining well-being.

2.2.1 'Going Home'

'Going Home' takes members through a regular roster of 3 weeks dialysis and training with WDNWPT RN 'Dialysis Trainers', operating together in a specially-prepared 'Dialysis House' located in suburban Alice Springs. Afterwards, the team of patient and trainer travel out to Kintore community for a further 3 weeks in the 'Dialysis Room', a suitable space within the local PHHS clinic.¹⁰³ Any WDNWPT member, on any RRT, can be supported. All participants are clinically reviewed by the nephrologist prior to entering the program, and MOUs between RDU and PHCS define roles and responsibilities. A local WDNWPT/RDU reference group meets 6-weekly, having developed terms of reference, to strengthen communication and address clinical or service issues.

2.2.1 a) Initial program development

A summary of program development is contained within Appendices 2 & 6. Specific plans arose after a Governing Committee trip in 2002 to Bidadanga, an community in the Kimberley, where Indigenous role models were seen doing their own dialysis. Committee members reflected how no-one had ever gone home on dialysis in their own region, and that all *Yanangu* should be given the opportunity. 'Going Home' would have health-benefits for all, and it was important that no-one should be excluded, even though some might never have the

support or skills necessary to achieve independence as required by mainstream ‘pure’ self-care. Without any direct, external financial assistance, WDNWPT dialysed its’ first member in the ‘Dialysis House’ in 8/04, and the ‘Dialysis Room’ in Kintore, 9/04. The advantageous situation of having a WDNWPT RN living in Kintore supported the first roster with 2 patients on HD together in 9/05.

2.2.1 b) Dialysis delivery

Full details of the dialysis delivery during ‘*Going Home*’ are placed in Section 5.0, Appendix 4. A total of 144 dialysis treatments were delivered over 9 months to 18 individuals by WDNWPT. Awkwardly, a 4-month hiatus due to WDNWPT RN changeover (4–8/05) meant data collection has continued until 10/05 to give more meaning. Predominantly HD (87%; 128/144), 56% of these treatments occurred within the ‘Dialysis House’, 44% in the ‘Dialysis Room’, Kintore. Only 1 scheduled treatment was missed due to vehicle breakdown, an attendance rate of 99.3%, as opposed to < 85% routinely for non-WDNWPT members in RDU.

2.2.1 c) Emerging patterns of use

Whilst complete dialysis rotations between town, bush and back were intended (76% of total rotations), two additional, distinct patterns emerged:

i) Aborted rotations

These comprised 13% (17/128) HD delivery, but affected 33% of individuals (5/15) intending to go out to Kintore. Despite assessment by the nephrologist immediately prior to commencing ‘*Going Home*’ program, 4/5 individuals required admission to hospital due to acute illness un-associated with the dialysis delivery, an unexpectedly high rate of attrition. None involved interruption of actual treatment whilst on the HD machine, whatever location.

ii) Limited rotations

17% (3/18) of program participants chose to go to the ‘Dialysis House’ intending only 1 weeks’ dialysis, for reasons detailed in 5.05 (Appendix 4).

On the basis of this activity, 12-month projected delivery associated with ‘*Going Home*’ would include 172 HD, at a total cost of \$73,530, excluding the 21 APD treatments costs.

The hiatus in dialysis delivery caused by the coincidental loss of both WDNWPT ‘Self-care Trainers’ RN within a month of each other (4/05), accompanied by the initial 6-month delay to ‘*Going Home*’ roll-out, placed timing constraints upon WDNWPT, and made aspects of the investigation of this program uneven. This was compounded by the necessary financial constraints placed upon systematic ‘Stage 1’ investigation by the lack of external funding for

more detailed research (see Appendix 3). WDNWPT was unfortunately unable to collect sufficient data on number of standard biomedical indicators of dialysis quality,¹⁰⁴ (comparing the progress of individuals before and after program intervention) and progress through self-care skills assessments.

2.2.1 d) *Yanangu* describing the impact of ‘Going Home’

During interviews, important issues were raised by *Yanangu*:

i) Optimism and hope

Members on dialysis, Governing Committee members and families all expressed happiness and optimism as they considered the opportunities to re-establish family relationships that ‘*Going Home*’ offered them.

*“I went for a three week holiday and stayed with family, which was great. Having the machine at Kintore gave everyone happy faces. “Oh you’ve been in town such a long time” they said,” Finally seeing you up close has made us happy.”*¹⁰⁵

Excitement grew amongst members in town as they waited their turn:

*“It’s really happening!” they said. They’ve all heard about it, it’s for real.”*¹⁰⁶

This optimism appeared especially important for those who had been in town a long time.

Governing Committee members stressed the impact felt by families everywhere out bush, not only in Kintore:

*“We are all happy for her. She came back so her daughter, her brother, sister, cousin, everyone could look after her. All of her family are sitting here like they are crying. Because of this, everybody across Kiwirrkurra and Kintore, we are all becoming excited and happy. And inside, in her heart, she’s feeling real happy now – sitting, listening to language with all the Pintupi people. She lived in town for a couple of years ... but to her family she has now truly returned to Kintore. Yes, poor bugger. We know others didn’t make it, but you know it’s finally happened. We know we’ve been sad, but we’re also happy.”*¹⁰⁷

ii) Rebuilding the quality of social interaction

Apart from brief, intermittent visits, now more systematic and frequent since ‘*Return to Country*’, WDNWPT members hadn’t spent an extended period of time at home with their families since they first left to live in town. On meeting their families once more they described their feelings using Pintupi terms of a ‘reconciliation from separation’, or ‘re-uniting after adversity’. The customary reciprocal relationships which fulfil needs of *walytja* could be rebuilt, so difficult to do when ‘dislocated’:

*“Oh they became happy (well). When they saw me they called me over, all my family. They looked after me the whole time and always gave money.”*¹⁰⁸

Many spoke of hunting trips, being able to participate in the social aspects of being with family, on traditional country, learning, listening, teaching. Grandmothers emphasised looking after grandchildren once more, an important customary role, as they could be ‘seen up close’. One granddaughter specifically noted the improved vitality of her grandmother whilst at Kintore, compared to town:

*“Oh my grandmother is always sleepy in town but here she seems alive.”*¹⁰⁹

The patient herself later mused how the young girl had “...*finally become really happy*”¹¹⁰ by seeing her so well. This particular individuals’ vitality was described later by WDNWPT staff, as she sang gospel on dialysis in the ‘Dialysis House’, an occurrence unheard of in RDU.¹¹¹

WDNWPT men on dialysis discussed the possibilities of a coordinated visit with ceremonial business. They were particularly concerned for one of the more remote, small communities whose very fragile existence depended on dwindling numbers of critical, senior elders, currently stuck in town on treatment. Though richer and more persistent relations arose through ‘*Going Home*’, families had to work hard. Spouses returned to households where they might no longer be wife or mother. New roles and old relationships can cause tensions, kept peaceful by distant separation. Extra mouths to feed and the demands of those with chronic disease all require careful negotiation by *Yanangu* and WDNWPT staff.

iii) Developing understanding (*kulini*)

Alongside strengthening family relationships, including non-Indigenous WDNWPT staff and transport in trips such as hunting had several intended outcomes. It is important in remote areas to ensure that vehicles are reliable, particularly through extremes of weather when carrying children and those with chronic illness. However such trips also assisted the development of necessary personal relationships required to provide secure cross-cultural care, especially when staff are out of their personal and institutional safety-zones in remote communities. *Yanangu* regard this as part of their relationship responsibility to make others ‘understand’ (*kulini*):

*“Us two went everywhere together ... All of us went for pura (bushtucker)¹¹² – we were always eating it, by the bucket-full! I finally took her to see my outstation, to show her so she’d understand. We went north of Kintore, where (WDNWPT employee name) took a photo of me with my nephew and niece in the bush.”*¹¹³

iv) The presence of the dialysis machine and WDNWPT team

“Some people are sick. Yanangu who are living with bad kidneys, this has been done for them first. Many people are healthy at Kintore, however some people have problems ... It’s for all the new ones as well, not just for all the old ones.” ¹¹⁴

Dialysis on the community met an immediate need, but the machines’ very presence allowed more complex issues to be opened up. Those ‘coming behind’, Yanangu with CKD or young people as yet unaffected, might be able to see the machine, think about it, even learn how to use it. In considering the latter, one interviewee, an experienced teacher, expressed particular concerns:

“When they see the dialysis machine happening at Kintore, or when they get sick, maybe that’ll make them think ... Many people have talked about dialysis. Since this problem started they’ve talked a lot about having it in their own community. It’s good to have a dialysis machine so young people can see and think about it, as it’s not only for old people.” ¹¹⁵

Some saw opportunities for older people to die in their own country, whilst others perceived difficulties. Discussion cannot be carried by individual members on dialysis alone, and the association of peer and trusted staff offering accurate information to community members and PHCS staff over extended periods of time. Seeing the machine was confronting for some with CKD, and the discussions repeatedly focused upon the dilemma of maintaining family relationships whilst being on a machine and avoidance of similar suffering as experienced by WDNWPT members.

v) Meeting members concerns

WDNWPT members on dialysis had asked Governing Committee and staff to hold the ‘Going Home’ plans for 6 months, until personal and dialysis ‘safety’ issues had been more broadly discussed (see Appendix 6). All patients at interview showed clear understanding of ‘Going Home’ arrangements, before, during and after:

“I’ve done dialysis well in the small house (Dialysis House, Alice Springs). Yanangu reckon it’s good that everyone has a turn for 3 weeks. When they come back, another goes to dialysis out there whilst someone else goes to the small house. Going round and round like that is alright they reckon. I like the two of them, the small house and out there in the clinic, it’s good. Here for 3 weeks doing dialysis, then moving out to Kintore.” ¹¹⁶

Generally members preferred the ‘Dialysis House’ over RDU, citing quiet and fewer people. The feeling was that the overall slower pace of dialysis, accompanied by family, were positive in both dialysis spaces:

“It’s good doing dialysis there in the correct way.” ¹¹⁷

2.2.1 e) Non-Indigenous description

WDNWPT interviews with non-Indigenous stakeholders in RDU noted a number of varied, positive outcomes, as enthusiasm for WDNWPT members and the program grew. A greater understanding of *Yanangu* lives outside dialysis arose with the palpable relief of isolation shared by patients, families and staff alike. The initial unease as to whether WDNWPT members would settle back into RDU after visits or even overstay was unfounded, rather a sense of a team identity began to be build. A sense of mutual ‘reverse respite’ was expressed:

“... There is probably an element of respite for us all, for staff like me who have been here for years and some of the patients who have been here for years. I’m sure we all do get a little bit sick of seeing each other three times a week, every week.” ¹¹⁸

PHCS staff expressed particular satisfaction with clinical management protocols established by WDNWPT via MOUs, but still voiced concern as to possible future roles in prevention or dialysis delivery.

2.2.1 f) Implications of “Going Home”

Isolated people without hope are unhealthy by any definition. This would include WDNWPT members on dialysis, families on remote communities or RDU staff. ‘*Going Home*’ has made a start in reversing this pessimistic outlook. WDNWPT has shown that single patient dialysis can be delivered in a remote region such as the Western Desert, and importantly it can be achieved through local partnerships with community, PHCS and RDU.

WDNWPTs’ preliminary investigation occurred during the start-up phase of ‘*Going Home*’. As in any formative relationship, further development requires sustained input from partners. However *Yanangu* are clear that the program has made progress in strengthening family networks and community coherence, and offers hope. In re-establishing and re-invigorating relationships, it has affected individuals, families and RDU staff in certain similar ways, reducing isolation and anxiety, with members attending astonishingly well. The actual presence of a machine, accompanied by peer and trusted professional sources of accurate information, have supported debate about CKD, dialysis, renal health and the avoidance of going to town.

The intention was never to make Kintore a dialysis ‘hub’. Current negotiations with Ngaanyatjarra Health support the inclusion of dialysis infrastructure within the new clinic to be constructed mid-2006. In consultation with this PHCS, WA Remote Dialysis and NT Renal Services, ‘*Going Home*’ will be developed accordingly.

The varied use of dialysis rotations in Alice Springs by *Yanangu* may alter further as time goes on, serving different interests: supporting those encountering difficulties with attendance and offering periods of longer sessions of treatment to those unstable on standard regimes. Self-care assessment and training should increase now that members have more knowledge of opportunities and belief in their delivery. However, self-care training was never a pre-condition for entry to ‘*Going Home*’, in contrast to mainstream services, but *Yanangu* have developed the understanding of the potential value that this has in returning home to live. Learning HD is lengthy and difficult, increasingly the support of APD delivery will be the WDNWPT issue. WDNWPT flexibility may develop further as a ‘release-valve’ for RDU and members encountering difficulties driven by the rigid necessities of a large, busy institution.

Underlying ill-health curtails a significant number of intended ‘*Going Home*’ rotations, emphasising the importance and success of management protocols negotiated to avoid dialysis-associated problems, whilst highlighting the long-term requirement to improve the overall health of the sick population within RDU. No matter how good the delivery, regional dialysis outcomes will remain impoverished if upstream co-morbidity care is poor.

The DHCS decision in 2005 to offer recurrent funding for the 2 RN ‘Self-care Trainers’ has provided WDNWPT with a useful basis for further development. It has not been without tension however. All remote dialysis funding comes from the identical ‘Acute Care’ bucket, and WDNWPTs’ position is now one of resource competition with its’ partners in NT Renal Services. Considerable care has been taken by WDNWPT to develop an understanding that such quality assurance indicators that are required are beneficial rather than restrictive, and respond to the different kind of service WDNWPT offers.

The manner in which the Commonwealth involves itself will be crucial from hereon. An SRA agreed in 6/05 funded the purchase of the ‘Dialysis House’ in Alice Springs. However, WDNWPT believes there is a clear role for Alice Springs-based PHCS and related organisations ‘reach into’ RDU to give reality to claims of ‘holistic care’ provision. Out bush, ‘*Going Home*’ offers opportunities to local PHCS for involvement around CKD and chronic disease care, but requires jurisdictional barriers to be overcome. WDNWPT will require more support to describe ‘*Going Home*’ activities whilst it focuses on service delivery, particularly to present a balanced view of biomedical and *Yanangu* health outcomes.

2.2.2 ‘Bereavement’ Process

This is the second of the two WDNWPT long-term developments. Internal WDNWPT documents form source material within this section.

During the course of routine contacts, professional and Governing Committee discussions, WDNWPT has been working with 5 particular member families whose relatives had passed away during the period 4/01–4/02. These families had received an array of second-hand information, were uncertain and unhappy as to the details, and sought discussion with a trusted, informed source. The deaths, so far from home, family and first-hand description, were acting as a cumulative stressor, reaching out to other patients on dialysis and their families. *Yanangu* described anger and violence towards themselves and health staff in the confusion and anxiety. In turn, this disrupted the resolution of financial, ceremonial, and community affairs. Beyond, there was a flow-on effect to those with CKD, influencing a resistance to accessing renal services and ensuing entry into the dialysis system in crisis. *Yanangu* described family members becoming ill from unresolved grief. The need to ‘finish-up’ this process was not just confined to *Yanangu*, as staff at RDU also needed such opportunity. In keeping with the Incorporation Objectives, the WDNWPT Governing Committee (6/02), who’s very name means “*Making all our families well*”, began to consider a process to seek resolution, for the individual families and for those ‘*coming behind*’. Such a resolution, literally to turn discord into concord, acknowledged several particular issues:

- whilst individual incidents were “family business”, WDNWPT has a responsibility to assist members understand all avenues of redress open, without providing specific legal support
- to avoid the situation where initial approaches to DHCS might become uselessly trapped within legal exchange, a delicate balance was needed between description and reasonable comment upon medical care, without compromising further individual legal choice
- the current dialysis care of WDNWPT members must not be jeopardised by any approaches
- an honest negotiation would be fundamental to negotiate the considerable cross-cultural views. The recent Banskott inquiry (2/03) gave some contextual hope in this regard, in that the proposed renal clinical stream would require “... *strategies to address facets of care that relate to awareness of patient rights, treatment options, communication and education that underpin all health service delivery.*”¹¹⁹

A 12-month internal WDNWPT process followed, including fieldwork to identify family members and seek possible conflicts of interest, establish known details and circumstances with families, clarify available options and finally reach consensus over an approach to DHCS.¹²⁰ Access was sought to review relevant medical files in conjunction with a NT Renal Service

nephrologist, and prepare written reports for families and DHCS. The objectives of the reports were:

- to offer detailed information and provide a basis for face-to-face conciliation meetings between DHCS (NT Renal Services), WDNWPT and families
- to form part of a broader, systematic conciliation process required to resolve issues of death and grief, especially by families and staff within RDU

Simultaneously, WDNWPT was delivering ‘*Return to Country*’ and ‘*Yanangu advocacy malpa*’ programs (see relevant sections), with the latter providing Memorial Services for members and staff and attempts to explore *Yanangu* issues related to grief with RDU staff. ‘*Bereavement*’ progress has been achingly slow and incremental. Following family consent to access files (see Appendix 7), the summary report was delivered to DHCS (11/04), and fed back to families by WDNWPT thereafter. Individual issues aside, it suggested that two important areas of communication difficulty experienced by families be addressed:

- the synergistic role of the Coroners Office should assist the proposed negotiations
- the institutionalisation of appropriate guidelines for dealing with death should be considered, such as those described by Weeramanthri *et al*¹²¹

Latterly the process has moved closer to face-to-face meetings. The Governing Committee has continued to try to emphasise that it is showing proper concern (*alturringu*) to families, in developing an approach that doesn’t cause further injury. The suggested processes involve an opportunity to explain the importance of ‘*Yanangu Way*’, including customary gestures of atonement, intending to “sooth the spirit” (*kurrunpa palintjaku*) so that relatives are no longer affected by sorrow and ensuing ill-health, and raising the possibility of a ‘Cleansing Ceremony’ (*Parrkatjarra yurranytjaku*). The 2-way process allows DHCS to describe its’ organisational view of two parallel streams – bereavement and grievance, with their associated complex thought and meaning.

The current challenge for WDNWPT and DHCS is to both acknowledge the differences whilst seeking enough common ground to make progress. Ultimately however, only the families themselves will be able to say whether its’ all been enough. Importantly, no other WDNWPT families have requested information about relatives on dialysis who have passed away after 4/02, despite the roll-call being seven in number. Unfortunately however, at the time of writing the process has stagnated as elements of DHCS struggles to engage meaningfully.

2.3 Monitoring Activities

As already described, the initial WDNWPT focus was to provide immediate ‘Lifeline’ programs whilst working with the Governing Committee to develop appropriate long-term plans alongside a governance structure to match. Over time, members’ concerns grew over the extent of ‘dislocation’ effects, the perceived inequality of renal services and RRT opportunities compared to non-Indigenous people, and the general lack of accurate, accessible information. By mid-2003, stakeholders also had an increasing interest in the WDNWPT process and services, further emphasising the necessity of ‘hard’ outcomes to inform impending funding negotiations in 2004/5.¹²² A concise description of WDNWPT advocacy and service provision would assist the Governing Committee to affirm the organisations’ direction, sharing the story with others, whilst broadening government negotiations to include simple routine quantitative indicators with the richer, though more uncertain qualitative contribution of *Yanangu* expressions of the maintenance of well-being.

The main report has already given an account of routine monitoring activities: governance, (including financial audit) and a narrative description using archived materials¹²³. In conjunction with these, a number of more specific activities were carried out during an intensive 12-month period of scrutiny (4/04–4/05). This systematic investigation arose from a collaboration with a small, expert team,¹²⁴ supported by seeding contributions from CRCAH¹²⁵ and NTDHCS,¹²⁶ alongside majority WDNWPT funding of 1.6 FTE researchers (\$100,000).

The investigation process is described in detail in a number of separate appendices:

- Appendix 3 outlines the investigation development
- Appendix 4 gives detailed results
- Appendix 7 describes *Yanangu* consent issues confronted by WDNWPT
- Appendix 8 summarises data collection and analysis
- Appendix 9 provides an analysis of the WDNWPT regional population denominator

Hey you readers! Kulila!

Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (“*Making all our families well*”) is a non-government organisation working to bring people home to Western Desert communities on dialysis.

Having got this far, you might want to support us in a few more ways!

- We have a Volunteer Program supported by the Alice Springs Town Council. People donate their time to help with picnics, our choir, driving, outings and other activities that help to make life in town bearable for *Yanangu* obliged to live far away from family and country.
- We are always looking for blankets, household goods, furniture, toys and just about anything to help set up new patients comfortably in town.
- We are a registered charity and welcome tax-deductible donations.

If you think you can help or just want to talk more about what we are doing and how *Yanangu* with kidney disease and their families are helping themselves, please contact:

Sarah Brown, Manager, WDNWPT:

PO Box 5060, Alice Springs, NT 0871

wdnwpt@bigpond.net.au

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Glossary

Access – a conduit for dialysis to occur, created via catheter tubes (Tenckhoff; subclavian) or joining forearm arteries and veins (see Fistula)

Automated Peritoneal Dialysis (APD) – PD exchange which is delivered by a small, regulated pump, usually overnight (see Peritoneal Dialysis)

Continuous Ambulatory Peritoneal Dialysis (CAPD) – PD exchange done at regular intervals during the day, taking around 20 mins (see Peritoneal Dialysis)

Community-based dialysis – Any dialysis option occurring within the community. Usually refers to single patient haemodialysis systems, but emphasises general location anywhere outside of an institution dedicated to dialysis delivery

Chronic Kidney Disease (CKD) – the situation of kidney disease deterioration prior to dialysis (previously known as Chronic Renal Failure; Chronic Renal Insufficiency)

Co-morbidity – illness accompanying CKD, usually type-2 diabetes and heart disease

Dependence – a measure of client requirements in meeting treatment opportunities. Often classified as mild, moderate, high, it may address different social and physical needs of individuals, aiming to achieve independent living and/or treatment

Dialysis – the treatment offered to replace that kidney function associated with removing toxic waste from the body. Currently of two kinds, haemo- and peritoneal dialysis

End-stage Kidney Disease (ESKD) – previously ESRF; ESKD

Fistula – by surgically joining arteries and veins in the forearm, bigger vessels are created for easy insertion of large-bore needles for haemodialysis (see Access)

Home-based dialysis – any dialysis option occurring at home. Often only thought of in reference to self-care haemodialysis, but simply emphasises location

Haemodialysis (HD) – a machine pumps blood from the body via needles, through a filtration system and back. Institutional treatment cycles usually last 4-5 hrs, 3 times weekly.

In-centre dialysis – any dialysis option occurring within an institution dedicated to dialysis delivery. Usually refers to treatment in hospital, but here includes the Renal Dialysis Unit (see RDU), emphasising the physical structure and customary practices associated with it

malpa – a companion or associate, one who shares experience (see Hanson *et al*)¹²⁷

Peritoneal Dialysis (PD) – a gentle, daily dialysis option which uses an individuals' abdominal cavity to achieve dialysis. It is almost exclusively done by patients themselves (see Self-care). Fluid is carefully exchanged at predetermined intervals, via a small, permanent artificial catheter (see Access)

Renal Dialysis Unit (RDU) – the regional institution 'responsible' for the full range of dialysis-associated services, located in Flynn Drive, Alice Springs. In fact, RDU is properly termed a satellite unit (see below), but the close relationship with the hospital (ASH), the broad range of dependent dialysis clients, and the housing of the Outreach and Self-care Training teams make it more than this.

Renal Replacement Therapy (RRT) – any form of treatment that replaces kidney function. Includes dialysis and transplant

Satellite unit – an institution managed by a hospital, with staff delivering outpatient dialysis services to more than 4 clients. Usually clients have a degree of independence (see Dependence)

Self-care – the ability to do your own dialysis treatment yourself

Town Camps – designated living areas for Aboriginal people within the Alice Springs town boundaries

Transplant – the situation where a client has received a replacement kidney from a donor, either a living relative or from someone deceased.

Yanangu – the Pintupi/Luritja term by which Indigenous people from the WDNWPT region use refer to themselves

Acronyms

ACCHO	Aboriginal Community-Controlled Health Organisations
ACR	Albumin / Creatinine ratio
AMSANT	Aboriginal Medicals Services Alliance of the Northern Territory
ANZDATA	Australia and New Zealand Dialysis and Transplant Association
APD	Automated Peritoneal Dialysis
ASH	Alice Springs Hospital
ATSIC	Aboriginal and Torres Strait Islander Corporation
CAAC	Central Australian Aboriginal Congress, (Alice Springs)
CAPD	Continuous Ambulatory Peritoneal Dialysis
CARI	Caring for Australians with Renal Insufficiency
CARIHPC	Central Australian Regional Indigenous Health Planning Committee, (Alice Springs)
CARSWAG	Central Australian Renal Social Well-being Action Group, (Alice Springs)
CKD	Chronic kidney disease
CRCAH	Cooperative Research Centre for Aboriginal Health
CRH	Centre for Remote Health, (Alice Springs)
DHCS	Dept. of Health and Community Services (NT)
DTR	Dialysis Treatment Record
Dx	Dialysis
ED	Emergency Department
ESKD	End-stage kidney disease
GFR	Glomerular Filtration Rate
HD	Haemodialysis
ICC	Indigenous Coordination Centre
ICU	Intensive Care Unit
I/P	In-Patients
KGH	Kalgoorlie General Hospital, WA
Menzies	Menzies School of Health Research, Darwin
MSOP	Medical Specialists Outreach Program
NTAHF	Northern Territory Aboriginal Health Forum
OATSIH	Office of Aboriginal and Torres Strait Islander Health
O/P	Out-Patients
PD	Peritoneal Dialysis
PHCAP	Primary Health Care Access Program
PHCS	Primary Health Care Service
PHHS	Pintupi Homelands Health Service (Kintore / Wałungurru)
Pt	Patient
RDH	Royal Darwin Hospital
RDU	Renal Dialysis Unit (in this report used exclusively to refer to Alice Springs)
RPH	Royal Perth Hospital, WA
RRT	Renal Replacement Therapy
SRA	Service Responsibility Agreement

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- ¹ S. Zimran Tjampitjinpa, 10/12/97. Interview with Jeannie Devitt, Alice Springs, NT.
- ² Banskott Health Consulting. Review of NT Dept of Health & Community Services. Unpublished report to NT Government, Darwin; 2003. (Item 303).
- ³ *Yanangu*: the term Pintupi/Luritja people from this region use to refer to themselves.
- ⁴ Primarily the momentum arose from Peter Toyne (then MLA for Stuart, NT), Tim Klingender (Sotheby's Australia), Smithy Zimran Tjampitjinpa (Pintupi statesman and dialysis patient), Hetti Perkins (Activist and Curator, Art Gallery of NSW) and Paul Sweeney (Papunya Tula Artists). Sir William Deane and Charles Perkins were co-patrons. Unfortunately the latter passed away from kidney disease prior to the auction, and Smithy Zimran just after. All efforts, products, services, publicity etc were donated entirely free throughout. To coordinate management, a small committee was formed, "Friends of the Western Desert Dialysis Appeal," which held the monies in trust until the project was underway.
- ⁵ Preamble to Sotheby's Auction catalogue (Western Desert Dialysis Appeal, 11th November 2000): *'Dialysis services in the Western Desert are non-existent...Those with kidney disease face the impossibly difficult choice of whether to relocate hundreds of kilometres away to Alice Springs, thereby uprooting their family (or leaving their family behind) and leaving their traditional homelands and culture; or whether to stay in their community without dialysis treatment, with the inevitable consequences. The monies raised from this appeal will be used by the Pintupi Homelands Health Service to assist with the establishment and maintenance of dialysis facilities at Kintore. ... Funds raised by the appeal will be used to cover costs over and above those allocated by the Federal and Territory governments for the treatment of the Pintupi Homelands dialysis patients in Alice Springs.'*
- ⁶ Marlene Nampitjinpa, Treasurer of WDNWPT, statement given in English (28/9/04).
- ⁷ Living areas range in size from extended family outstations to small regional centres of a few hundred people. Basic services include primary schools, clinics (PHCS) and local administration.
- ⁸ See Myers F. 1986 (ibid) for detailed discourse on this.
- ⁹ Western Desert Dialysis Appeal. 'Your place or mine' – dialysis in Central Australia'. Proceedings of the 5th World Conference on Rural Health, WONCA; May 2002; Alice Springs, Australia. (<http://www.crh.flinders.edu.au/wonca/papers/finalwoncap.pdf>)
- ¹⁰ Devitt J, McMasters A. Living on Medicine: a cultural study of end-stage renal disease among Aboriginal people. IAD Press, Alice Springs; 1998.
- ¹¹ Myers F. Pintupi Country, Pintupi Self: Sentiment, Place and Politics among Western Desert Aborigines. Australian Institute of Aboriginal Studies, Canberra. 1986. This excellent resource recounts Pintupi anxiety in Papunya becoming unwell "...from sorcery by hostile strangers..." (p.38).
- ¹² LzM (28), WDNWPT evaluation interview.
- ¹³ OtM (L 22-31 follow-up questions). WDNWPT evaluation interview.
- ¹⁴ Myers also explains 'watjilpa' (ibid, p.119), a term covering "... "homesickness", "pining", "lonely", "worry" or "melancholy". At its core it refers to separation from objects or persons of security and familiarity – places and people among which and with whom one grew up and where one feels safe and comfortable."
- ¹⁵ Finklestein FO & SH. Psychological adaptation and quality of life of the patient with end-stage renal disease. In: Brown E, Parfrey P, editors. Complications of long-term dialysis. Oxford University Press; 1999. The authors give a detailed summary of psychological and social problems faced by people on long-term dialysis, with a range of morbidity figures.
- ¹⁶ IL (197), WDNWPT evaluation interview.

- ¹⁷ Hempel R., Kimber R., Stead J, Styles R. Kintore Review: 1/4 March 1982. Dept. of Aboriginal Affairs & Dept. of Community Development, Darwin; 1982.
- ¹⁸ (1) Nathan P, Japanangka D L, Settle down country: Pmere arlatyewe. Central Australian Aboriginal Congress (CAAC), Alice Springs; 1983. (2) Settle Down Country (video). Darlinghurst NSW: Sydney Filmmakers Co-operative, for the CAAC; 1983. (3) Hempel R, et al. 1982 (ibid). (4) Myers F. 1986. (ibid). (5) Malbunka M. When I was little, like you. Allen & Unwin; 2003. Mary, a WDNWPT patient on dialysis in Alice Springs, writes a beautiful story about growing up in Papunya during the early 1960s. Her description is in sharp contrast with the historical accounts of the period portraying a situation deemed genocidal by some.
- ¹⁹ AnV (27/9/04), WDNWPT evaluation interview.
- ²⁰ Smithy Zimran Tjampitjinpa in Devitt J, et al. 1998 (ibid, p.5).
- ²¹ Nelson RG, Diabetic renal disease in transitional and disadvantaged populations. *Nephrology*. 2001;6:9–17
- ²² McDonald SP, Russ GR.. Current incidence, treatment patterns and outcome of end-stage renal disease among indigenous groups in Australia and New Zealand. *Nephrology*. 2003;8;1;42–8
- ²³ Cass A, et al. End-stage renal disease in Indigenous Australians: a disease of disadvantage. *Ethnicity and Disease*. 2002;12(3):373–378
- ²⁴ ATSIC: Aboriginal & Torres Strait Islander Commission, dissolved 2005.
- ²⁵ Cass A, Cunningham J, Wang Z, Hoy W. Regional variation in the incidence of end-stage renal disease in Indigenous Australians. *Med J Aust*. 2001;175(1):24-7.
- ²⁶ Bailie R, et al. Atlas of health-related infrastructure in discrete Indigenous communities. ATSIC/ Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH), Darwin; 2002.
- ²⁷ Northern Territory Aboriginal Health Forum (NTAHF). Draft report: Northern Territory Renal Strategic Plan 2003–2007– Integrating Renal Services across the NT: a necessary progression. NTAHF, Darwin; April 2003.
- ²⁸ Cass A, Gillin AG, Horvath JS. End-stage renal disease in Aboriginals in New South Wales: a very different picture to the Northern Territory. *Med J Aust*. 1999;171(8):407-410.
- ²⁹ Cass A, Cunningham J, Wang Z, Hoy W. Regional variation in the incidence of end-stage renal disease in Indigenous Australians. *Med J Aust*. 2001;175(1):24-7.
- ³⁰ Collectively known also as ‘Metabolic Syndrome’ or ‘Syndrome X’.
- ³¹ Banskott Health Consulting. Review of NT Dept of Health & Community Services. Unpublished report to NT Government, Darwin; 2003.
- ³² One model provides an ‘ecosocial’ framework, suggesting possible pathways that embrace this mosaic: Cass A, Cunningham J, Snelling P, Wang Z, Hoy W. Exploring the pathways leading from disadvantage to end-stage renal disease for Indigenous Australians. *Social Science and Medicine*, 2004;4:767–85.
- ³³ “*Social inequality is also deeply embedded: Indigenous people are poorer, have lower education levels, low literacy, high levels of unemployment, inadequate housing, high levels of substance misuse and very poor health.*” Northern Territory Aboriginal Health Forum (NTAHF), 2003 (ibid, p.7).
- ³⁴ Devitt J, McMasters A. Living on Medicine: a cultural study of end-stage renal disease among Aboriginal people. IAD Press, Alice Springs; 1998.
- ³⁵ Devitt & McMasters; 1998 (ibid). Chapter 6.
- ³⁶ S. Zimran Tjampitjinpa, 10/12/97. Interview with Jeannie Devitt, Alice Springs, NT.
- ³⁷ Central Australian Rural Practitioners Association. CARPA Standard Treatment Manual. 4th ed. Alice Springs; 2004.

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- ³⁸ Hoy W, et al. Secondary prevention of Renal and Cardiovascular disease: results of a renal and cardiovascular treatment program in an Australian Aboriginal community. *J Am Soc Nephrol*. 2003;14:S178–S185.
- ³⁹ Northern Territory Aboriginal Health Forum (NTAHF), 2003 (ibid).
- ⁴⁰ Both ACCHOs–Aboriginal Community–Controlled Health Organisations, whose representative body is AMSANT–Aboriginal Medical Services Alliance of NT.
- ⁴¹ Predominantly via renal protective, antihypertensives known as ACE inhibitor drugs.
- ⁴² O’Sullivan C, Brady S, Kidney Failure, Everybody’s business. *Nephrology*. 2004;9:S117–120.
- ⁴³ Central Australian Rural Practitioners Association. CARPA Standard Treatment Manual. 4th ed. Alice Springs; 2004.
- ⁴⁴ Weeramanthri T, et al. Northern Territory Preventable Chronic Diseases Strategy–Promoting an integrated and Life-course approach to chronic disease in Australia. NT Department of Health & Community Services Darwin, NT; 1999.
- ⁴⁵ Four levels of disease prevention can be considered (after Beaglehole R, et al. *Basic Epidemiology*, WHO, Geneva; 1993):–Primordial which aims to avoid the emergence/establishment of social, economic and cultural living patterns that contribute; Primary aiming to limit incidence by causation and risk control; Secondary aims to cure patients and reduce serious consequences through early diagnosis and management; Tertiary aims to reduce progress or complications of established disease.
- ⁴⁶ Northern Territory Aboriginal Health Forum (NTAHF). Draft report: Northern Territory Renal Strategic Plan 2003–2007– Integrating Renal Services across the NT: a necessary progression. NTAHF, Darwin; April 2003.
- ⁴⁷ Steve Dunham, NT Government Minister for Health. Radio interview with Fred McCue (transcript), 8DDD, 12/11/99.
- ⁴⁸ Northern Territory Aboriginal Health Forum (NTAHF), 2003 (ibid).
- ⁴⁹ OK (15/12/05), ZQ (11/1/05), WDNWPT evaluation interview.
- ⁵⁰ This role is evolving, facing considerable difficulties with the breadth of intended activities, but focuses on CKD patients, EPO treatment of anaemia, coordination of fistula creation and maintenance of relevant population lists, whilst discussing RRT options with individuals, often hospitalised acutely.
- ⁵¹ Banscott Health Consulting; 2003 (ibid).
- ⁵² ZM: PHCS referral letter. WDNWPT evaluation data.
- ⁵³ UJ, WDNWPT evaluation data.
- ⁵⁴ RJ, WDNWPT evaluation data.
- ⁵⁵ LS, WDNWPT evaluation data.
- ⁵⁶ (1) Devitt & McMasters; 1998 (ibid). (2) Cass A, Lowell A, Christie M, Snelling P, Flack M, Marrnganyin B, Brown I. Sharing the true stories: improving communication between Aboriginal patients and healthcare workers, *Medical Journal of Australia*. 2002;176:466–470
- ⁵⁷ IL (260), WDNWPT evaluation interview.
- ⁵⁸ AnV (173–195), WDNWPT evaluation interview.
- ⁵⁹ It’s not only the consultative approach that may be seen as harmful: “*I lived with Rheumatic Fever a long time ago. I was stabbed every month, every month always being speared. Continually being pierced with a needle ... still they kept piercing me.*” LL (0-2) WDNWPT evaluation interview.
- ⁶⁰ AMt, WDNWPT evaluation data.
- ⁶¹ LL (556), WDNWPT evaluation interview.
- ⁶² By ANZDATA convention, ‘Late’ Referral (LR) to a Specialist falls within a period 3 months before 1st haemodialysis.

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- ⁶³ Early use of temporary catheter access; increased likelihood of HD as the 1st dialysis choice; negative morbidity & mortality on dialysis; extended, expensive hospitalisations.
- ⁶⁴ Available from: <http://www.hdcn.com/calcf/gfr.htm>
- ⁶⁵ Hoy, W. *et al*, 2003, Secondary prevention of Renal and Cardiovascular disease: results of a renal and cardiovascular treatment program in an Australian Aboriginal community. *J Am Soc Nephrol*, 14:S178–S185
- ⁶⁶ Knight J, editor. CARI–Caring for Australians with Renal Impairment. Excerpta Medica Communications, Chatswood; 2000.
- ⁶⁷ The total population of peripheral WDNWPT communities has been counted (eg. Warakuna, WA), where a substantial portion aren't identified as members, or seek renal services from Kalgoorlie/Perth and elsewhere (see Appendix 9).
- ⁶⁸ Kneipp E, et al. Bring me home: Renal dialysis in the Kimberley. *Nephrology*. 2004;9:S121–S125.
- ⁶⁹ Australia and New Zealand Dialysis and Transplantation Registry. ANZDATA Registry Report 2004 (27th Annual Report). Adelaide, South Australia.
- ⁷⁰ Gorham G. Prevention and Treatment options for Renal Disease in the Northern Territory (with particular reference to the Barkly Region). Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH), Darwin; 2001.
- ⁷¹ 51% in Darwin. Source: NT Dept. Health & Community Services. Renal Services Strategy: aiming for world's best practice. NT Government, Darwin; 2005.
- ⁷² ZM (pre-53), WDNWPT evaluation interview.
- ⁷³ J. Swao, personal communication.
- ⁷⁴ S. Zimran Tjampitjinpa, interview with J. Hulcombe 22/9/97; 17/11/97. See also Keefe K. From the Centre to the city: Aboriginal education, culture and power. Aboriginal Studies Press, Canberra; 1992.
- ⁷⁵ A system of patrimonial subsections, allocated at birth. Men (tj–), women (n–): Tjapangati, Tjapanangka, Tjapaltjarri, Tjungurrayi, Tjampitjinpa, Tjangala, Tjakamarra, Tjupurrula. See Myers F. 1986 (ibid) for detailed discourse on this.
- ⁷⁶ AnV (431), WDNWPT evaluation interview.
- ⁷⁷ AnV (264), WDNWPT evaluation interview.
- ⁷⁸ AnV (245), WDNWPT evaluation interview.
- ⁷⁹ IdL (291), WDNWPT evaluation interview. This individual was directly asked about her use of compassion (*alturringu*): “I spoke like this, “Poor me.” That means that I feel sorry for myself when I'm in town, because it's lonely here without my relatives. Also the patients feel sorry for themselves when they're in town without relatives. And I would ask my husband (name), “What are you thinking now? What are you thinking to do now?” And he would talk like I just said, about being sorry for himself and wanting to go”.
- ⁸⁰ OtM (L1–69), written testimony.
- ⁸¹ Recorded by J. Hulcombe 17/11/97. For discussion, see Zimran S. ‘In our hands’. In Wright A, editor. Take Power. Institute of Aboriginal Development, Alice Springs p. 354-356
- ⁸² Labonte R. Community development and partnership. *Canadian Journal Of Public Health*. 1993;84:237–240
- ⁸³ These are in addition to involvement at formal Corporation meetings, including 2 permanent positions on the Governing Committee.
- ⁸⁴ WDNWPT Treasurer.
- ⁸⁵ “A renal dialysis unit is an enormous difficult thing to maintain. Keeping sterility, keeping the technical skills up. It's something that no-one in the world has ever been able to make work in the desert. I understand the people at Kintore wanting it, but there are enormous

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- difficulties because it would be a world-first (laughs) if it worked*". Available from: <http://www.abc.net.au/news/regionals/alice/monthly/regalice-25jan2001-2.htm>
- ⁸⁶ Literally “*sat hard*” LzM (88), WDNWPT evaluation interview.
- ⁸⁷ LzM (88), WDNWPT evaluation interview.
- ⁸⁸ This refers to the earlier generations’ experience of being moved to live in Papunya (see ‘*Dislocation*’ p.13).
- ⁸⁹ LzM (95), WDNWPT evaluation interview.
- ⁹⁰ LzM (88), WDNWPT evaluation interview.
- ⁹¹ See Appendix 8 for sample etc.
- ⁹² ZQ (321), WDNWPT evaluation interview.
- ⁹³ OK (15/12/05), WDNWPT evaluation interview.
- ⁹⁴ OK (568), WDNWPT evaluation interview.
- ⁹⁵ WDNWPT internal document: *Patient Support Worker job description* (6/01)
- ⁹⁶ “*Self-reported staff activities June–July 2004*” An internal WDNWPT document summarising investigation completed as part of systematic monitoring activities.
- ⁹⁷ WDNWPT internal documents: *Job descriptions–’YAM’, Manager, Community Development*
- ⁹⁸ Central Australian Regional Social & Well-being Action Group
- ⁹⁹ UJ (130), WDNWPT evaluation interview.
- ¹⁰⁰ LS (pre 105), WDNWPT evaluation interview.
- ¹⁰¹ Myers F, (ibid) 1986. p.134.
- ¹⁰² NT Dept. Health & Community Services. Renal Services Strategy: aiming for world’s best practice. NT Government, Darwin; 2005.
- ¹⁰³ Pintupi Homelands Health Service (PHHS), a Commonwealth-funded PHCS.
- ¹⁰⁴ These included individual DTR (see 4.0; Appendix 4), monthly URR and subsequent individual attendance at RDU.
- ¹⁰⁵ ZM (post 11), WDNWPT evaluation interview.
- ¹⁰⁶ LS (pre 67), WDNWPT evaluation interview.
- ¹⁰⁷ AnU (290), WDNWPT evaluation interview.
- ¹⁰⁸ LS (post-17), WDNWPT evaluation interview.
- ¹⁰⁹ WDNWPT internal document: *JH diary, 24/11/04*.
- ¹¹⁰ ZM (post 38), WDNWPT evaluation interview.
- ¹¹¹ QG (85), WDNWPT evaluation interview.
- ¹¹² *Solanum chippendalei*.
- ¹¹³ LS (post 55), WDNWPT evaluation interview.
- ¹¹⁴ LzM (47), WDNWPT evaluation interview.
- ¹¹⁵ OtM (32-54; 66-84), WDNWPT evaluation interview.
- ¹¹⁶ ZM (post 78), WDNWPT evaluation interview.
- ¹¹⁷ LS (pre 118), WDNWPT evaluation interview.
- ¹¹⁸ AQ (216), WDNWPT evaluation interview.
- ¹¹⁹ Banskott Health Consulting, 2003 (ibid). Item 13.
- ¹²⁰ This part of the process received valuable support from Central Land Council, Alice Springs.
- ¹²¹ Weeramanthri T. Practice Guidelines for Health Professionals (medical practitioners, nurse practitioners and Aboriginal Health Workers) dealing with the death of an Northern Territory Aboriginal person. Menzies School of Health Research, Darwin; 1996.
- ¹²² Stakeholders at this point included CRC(ATH) in research; DHCS in renal services (Acute Care management, policy, NT Renal Services) and Alice Springs Hospital (medical and RDU); Commonwealth (OATSIH and subsequently OIPC) and PHCS; local politicians.
- ¹²³ Including minutes of Governing Committee meetings, staff diaries and submissions.

¹²⁴ Gai Wilson and Jon Willis (Centre for Development and Innovation in Health, La Trobe); Paul Lawton (nephrologist, Royal Darwin Hospital); Jeannie Devitt (CRCAH). Ilan Warchivker (CRH health economist) and Stephen Halpin (Menzies School of Health Research) joined later.

¹²⁵ \$20,000, received 2/04.

¹²⁶ \$26,000, received 4/04.

¹²⁷ Hansen K. C., (1992) Pintupi/Luritja Dictionary, 3rd edition, Institute for Aboriginal Development, Alice Springs, NT