

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



## **Summary Report • November 2006**

Paul Rivalland for Western Desert Nganampa Walytja Palyantjaku Tjutaku

*Yanangu* Providing their own Kidney Dialysis Services  
as Indigenous People from the Western Desert, Central Australia



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A short report by Paul Rivalland on the activities of  
Western Desert Nganampa Walytja Palyantjaku Tjutaku:  
*'Making all our families well'*



**Yanangu Providing their own Kidney Dialysis Services  
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and Cooperative Research Centre for Aboriginal Health, 2006

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Title quote from Bobby West Tjupurrula, WDNWPT Chairman, April 2004

Warning: This report may contain images of people who have since passed away.

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# Foreword

**Don Palmer MA, ThL  
and Graham Bidstrup  
Directors  
The Jimmy Little Foundation**

After Jimmy Little's kidneys failed a few years back he continued to travel across Australia. He had to dialyse four times a day as he went, but he wanted to be with his Indigenous brothers and sisters and encourage them as they faced the same problems. Jimmy hoped his music might provide some comfort and even some healing. After he received a transplant he wanted to keep travelling and bringing hope to others struggling with kidney failure.

Last year Jimmy went back to Waḷungurru [Kintore]. Travelling on the small plane with him was a woman who was returning to her Country for the first time since she was on dialysis in Alice Springs. She shuffled onto the plane, bowed down by the weight of her problems. As she travelled over the West MacDonalḍ Ranges she began quietly singing the Dreaming songs of her Country. By the time the plane landed in Waḷungurru her eyes were sparkling, she stood tall and the expression on her face became radiant. Jimmy was moved to then meet the extraordinary people who ran this amazing *Return to Country* program. He spent time with those who were home on dialysis and he said it was so obvious what this meant not only to them, but to their families and their Community. They told him that the Dreaming of the two mountains that stand either side of the Community call people back. It was true.

The work of the Waḷungurru Community is regarded nationally, and even internationally, as groundbreaking. Others are being inspired by their example to create their own solutions along these lines when facing similar situations. These are solutions that are culturally appropriate and totally innovative.

It's difficult for people who have never been to a remote Community, or met the people, to grasp what all this means. To experience the distress of kidney failure and be sent hundreds of kilometres away to be stuck in other people's Country, not speaking the language, separated from those who give them a reason to live would break the toughest spirit. But the spirit of the *Anangu* is very strong. They have understood the problem and created their own solution. And it works.

Jimmy says that we can all learn from the *Anangu* way but also from their spirit and generosity. Now they want to share their story with others, even when the temptation must be to focus their energy on their own survival. Jimmy and his Foundation are committed to doing everything possible to support them, and we are proud to join so many others on that journey.



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# Foreword: 2

**Dr Paul Lawton**  
**Director**  
**NT Renal Services**

For most working with people with kidney disease in remote Australia, the problem of social dislocation has been known for many years. It has often been a story of hopelessness and despair.

Due to the strength of vision of individuals and their self-determination, Western Desert Nganampa Walytja Palyantjaku Tjuṯaku has been able to explore and explain the problem in detail from a variety of perspectives (*Yanangu*, health professionals, funding groups), engage positively with government at several levels to discuss possible solutions and act to deliver solutions that have made a large, meaningful difference to the lives of patients, their families and communities and to the broader community as a whole.

It is a story that many of us can and have learnt and benefited from: I hope that it is a story that is only beginning and that many more can take heart from and be a part of.

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*I now want to make a statement about people, about renal patients...  
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...  
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



Amy Nampitjinpa and family

*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,  
first WDNWPT member to return home on dialysis, April 2004

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# Acknowledgments

This report and the longer version upon which it is based would not have been possible without committed supporters. Full acknowledgments are made in the full report. However, in this summary report, particular acknowledgment is given to the WDNWPT Governing Committee, Hetti Perkins, Tim Klingender, Colin Laverty, Peter Toyne, Paul Sweeney, Andrea Rolfe, John Wakerman, the Bidyadanga community, *Waltja Tjuṯangu Palyapayi*, Fred Ordynski, Gill Gorham, Gai Wilson, Jon Willis, Mick Gooda, plus a host of others involved and the *Yanangu* participants — thank you. Further assistance in finishing the reports was provided by Jenny Brands, Barbara Beacham and Jane Yule.

We would like to acknowledge the work of the Western Desert artists who contributed their artworks to the initial auction and subsequent fund-raising activities. Four of their paintings are reproduced on the covers of this report.

We also gratefully acknowledge all the photographers whose photos appear in this report and thank them for allowing us to reproduce their work.

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WDNWPT Governing Committee, June 2005

*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

*Absent:* Cameron Tjapaltjarri Brown

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# Yanangu Country: Remote Communities in WDNWPT Area



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Kintore Community



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# Author's Note: About this Report

This summary report is drawn from a full report, which represents a lengthy, detailed description of the development and activities of Western Desert Nganampa Walytja Palyantjaku Tjuṯaku (WDNWPT), an Aboriginal organisation representing people on dialysis. Documented activities occurred between April 2001 and mid-2005. Copies of the full report, which includes nine appendices, can be obtained from the Cooperative Research Centre for Aboriginal Health's (CRCAH) website at: [www.crcah.org.au](http://www.crcah.org.au)

The full report includes comprehensive data from the systematic monitoring carried out by WDNWPT (enabled by a successful fund-raising effort) into the situation confronting those *Yanangu* Aboriginal people with chronic kidney disease living in the Western Desert region of Central Australia. It outlines the formation of WDNWPT, the rigorous quantitative and qualitative data collection and analysis undertaken, the battle to implement several innovative strategies — *Yanangu Advocacy Malpa, Return to Country, Going Home* and *Bereavement* — to counteract the appalling health outcomes that existed, and the role of monitoring activities to engage fundholders and to highlight the organisation's significant ongoing success.

This investigation took more than two years and was undertaken by myself and Jeff Hulcombe, with significant support from Jeannie Devitt at the CRCAH, Stephen Halpin from Darwin's Menzies School of Health Research, Paul Lawton at the Northern Territory Department of Health and Community Services, Ilan Warchivker from the Centre for Remote Health and WDNWPT's manager, Sarah Brown, at the behest of the WDNWPT Governing Committee. As part of the work, extensive interviews were carried out with key WDNWPT members, and quotes from these interviews can be found throughout both reports. All comments were freely offered, and every effort has been taken to maintain individual confidentiality where requested.

Shared *Yanangu* identity and determination set the WDNWPT priorities to develop and institute services that met their own needs. Such identity embraces many cultural-specific determinants that focus on a life-long requirement to nurture family, Country, Law and Dreaming. The project was entirely self-funded by *Yanangu* and, as such, is an inspiring story of Aboriginal people's ability to attain good health outcomes when given the autonomy and the financial independence to do so.

This summary report has been compiled for several key reasons, which include:

- Telling an inspiring story of Aboriginal self-determination.
- Providing more evidence of the clear health benefits to Indigenous groups of maintaining living relationships with family, home and Country.
- Reaching out to a wide audience to describe the pride in community success.
- Getting organisations interested in funding WDNWPT into the future.
- Informing policy-makers of a successful approach to the provision of health services to remote Indigenous communities.
- Attempting to publish Indigenous voices and experience of mainstream healthcare delivery, and redress the imbalance of a lack of consumer input.
- Reaffirming the faith placed by philanthropists in supporting Indigenous innovation.

**Paul Rivalland, October 2006**

**In the [Northern Territory] 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 2003<sup>1</sup>

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# The Founding of WDNWPT: Philanthropy and an Extraordinary Art Auction

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

Auction night was a huge success: Australian and international collectors had donated thirty-one original works of art by Australian Indigenous artists, alongside a further four specially commissioned collaborative paintings done by senior Pintupi men and women from Waḷungurru (Kintore) and Kiwirrkurra. Just over \$1 million was generated from their sale to global bidders, including \$300,000 paid by Kerry Stokes for the Kiwirrkurra Men's painting. The money was used to fund the development and subsequent activities of Western Desert Nganampa Walytja Palyantjaku Tjuṯaku or WDNWPT (literally '*Making all our families well*'), an organisation representing those *Yanangu* families on dialysis.

The appeal was the culmination of more than twelve months' effort by a unique partnership formed between *Yanangu* and those involved in the national Aboriginal art industry, local politics and Aboriginal community-controlled health services. Important individuals provided sustained momentum: Smithy Zimran Tjampitjinpa (Pintupi statesman and dialysis patient), Peter Toyne (then MLA for Stuart, NT), Tim Klingender (Sotheby's Australia), Hetti Perkins (Activist and Curator, Art Gallery of NSW) and Paul Sweeney (Papunya Tula Artists), with Sir William Deane and Charles Perkins acting as co-patrons. Sadly, just prior to the auction Charles Perkins passed away from kidney disease, tragically followed by Smithy Zimran a few months later from the same illness.

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**I arrived here [at the RDU in Alice Springs] 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?"**

WDNWPT member

**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], 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 [i.e. 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.**

WDNWPT member



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# The Big Issues: Dialysis and ‘Dislocation’ (the *Yanangu* Experience)

*Yanangu* who live in this disadvantaged, remote region of the Western Desert endure the highest rates of kidney failure in Australia. Until recently, those suffering from kidney disease have had no choice but to move hundreds of kilometres away for treatment to the regional Renal Dialysis Unit, or RDU, in Alice Springs, the largest single dialysis complex in the Southern Hemisphere. During the investigation period covered in this report, 41 per cent of the WDNWPT members on dialysis passed away. After only knowing of their kidney disease for an average of just over two years they then survived two and a half years on dialysis, a significantly shorter amount of time than their non-Indigenous counterparts nationally.



Renal Dialysis Unit, Alice Springs

Until 2001, all *Yanangu* received institutional haemodialysis by default within the RDU. This, the most expensive renal replacement therapy option, required families, carers and patients to live permanently in the Alice, with 100 per cent arriving from remote locations. In contrast to the situation nationally, no one had ever received community-based care.

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WDNWPT's investigation described *Yanangu* experiencing late diagnosis of kidney disease out bush, followed by poor communication during individual clinical consultations and then between services. Rapid disease deterioration ensued along with an inadequate preparedness for entry onto dialysis, excessive hospitalisation due to their critical condition, poor attendance at routine dialysis and, ultimately, reduced survival time. This legacy is enmeshed with an impoverished quality of life, alongside significant social effects upon the regional communities as *Yanangu* are obliged to persevere in Alice Springs. As one WDNWPT member simply stated: 'Family members who stay too long in town are dying, one after the other they all die.'

Such poor outcomes underscore a failure to address expressed *Yanangu* needs as to how to maintain their wellbeing. *Yanangu* dialysis patients suffer a sense of 'dislocation', their cumulative experience when obliged to leave behind their homes and families to receive treatment for renal failure in the RDU. Living in Alice Springs on dialysis brings with it complex negative emotions — shame (*kunta*), loneliness, despondency and depression (*tjituru tjituru; tjiluru; watjilpa*) — which affect individuals, family **and** Country **and** Dreaming alike. In turn, these then diminish *Yanangu* health (*kuyarringu; kurrarringu*), so that they become sick (*pikatjarra, miintarringu*) or pass away (*wiyarringu*) much earlier than they should.

*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.*

(WDNWPT member)

The significance of 'dislocation' for *Yanangu* is that it works against holding on to their very sense of identity and wellbeing. These attributes are expressed through fundamental, interconnected cultural values of family (*walytja*), Country (*ngurra*) and Dreaming (*tjukurrpa*). The impact of 'dislocation' on the health of dialysis patients, and upon their families and community, is so profoundly negative — and dealt with in such an inadequate manner by mainstream services — that *Yanangu* took the initiative of raising enough money to establish their own quality renal services.

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# The Initial Situation

## Confronting WDNWPT

The traditional country of WDNWPT members is an arid landscape, dominated by mesa outcrops, sandhills, spinifex plains and ephemeral waters. In the period after the auction, the situation for *Yanangu* — who despite being geographically dispersed maintain strong links through kin and extended family networks, alongside shared rights in Country — can be characterised according to three linked areas:

1. There were confronting descriptions of the loneliness, anguish and difficulties facing *Yanangu* members on dialysis in Alice Springs. Urgent responses were required to offer compassionate assistance.
2. Any new organisation would be delivering services within a complex regional context of kidney disease, health and multiple stakeholders.
3. To meet *Yanangu* needs, the development of a non-government community-controlled organisation was required, one that blended service delivery and advocacy within a responsive governance structure.



Country near Kintore

*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.*

WDNWPT member

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## The regional context of dialysis

Dialysis is one downstream point along a pathway of chronic disease care. Upstream, when kidney function begins to deteriorate, its onset and duration is uncertain but can be delayed by primary health care interventions. Chronic kidney disease is usually symptomless, and reduced kidney function is often identified during routine clinical consultations for other common chronic conditions such as diabetes. End-stage kidney disease is defined when kidney function is reduced to 5 per cent of normal function, and renal replacement therapy, of which dialysis is the most common, is required to sustain life thereafter. (A glossary of kidney disease-related terms is included on page 52 of the full report.)

In Australia, the highest rates of chronic and end-stage kidney diseases occur within remote, regional, Indigenous communities characterised by rapidly changing lifestyles, relative poverty and disadvantage. Of the top four worst affected Aboriginal and Torres Strait Islander Commission regions nationally, Warburton and Apatula (third and fourth) straddle the WDNWPT area. With limited infrastructure, which is also of significantly reduced quality, the regional population has extremely poor health, low levels of formal education and little or no employment. Although not all Indigenous groups are affected equally by end-stage kidney disease, Northern Territory rates are now some thirty times higher than the national figure, accelerating over the past few decades in conjunction with the co-existing conditions of type-2 diabetes and ischaemic heart disease.

The cause of end-stage kidney disease is not simple but certainly includes such diverse determinants as socio-economic disadvantage, low birth-weight and the institutional racism that has been operating in Australia since colonisation. *Yanangu* describe how processes that undermine individual and community coherence and wellbeing, including well-intentioned dialysis treatment services, exacerbate and cause ill-health.

By 2001, burgeoning numbers of dialysis patients in the Northern Territory were severely stressing the existing strategic response to renal service delivery in Central Australia, historically focused upon institutional haemodialysis within regional centres and active discouragement of community-based options. This was in stark contrast to the national situation, particularly in Western Australia where an inspirational remote dialysis program had been developing for more than a decade. The lack of integrated regional policy and political will to coordinate responses, plus increased workload and staff turnover within the Alice Springs RDU, added to a developing sense of isolation, frustration and crisis for both patients and staff.

As part of WDNWPT's preliminary, systematic investigation (for details of this see Appendix 3, 4, 7, 8 and 9 in the full report), the progress of the first twenty-seven WDNWPT members on dialysis were retrospectively tracked along the pathway of care. This included primary and tertiary health services out bush and in town, mindful of their respective State/Territory and Commonwealth fundholder jurisdictions. The intention was to describe *Yanangu* experience up to and including dialysis, so as to build a more complete picture for members and fundholders.

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## Yanangu knowledge of renal disease and regional services

Yanangu feelings at the time focused upon the ‘dislocation’ experienced by family members undertaking treatment in Alice Springs, and on their poor survival rates and inadequate levels of care compared to non-Indigenous counterparts. Knowledge of dialysis options and delivery was limited. Yanangu frustration was compounded by their inability to influence existing non-Indigenous biomedical views of disease causation, care and treatment services, in order 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.*

Smithy Zimran Tjampitjinpa

The negative impact of this prevailing dismal outlook was highlighted for ‘those coming behind’ — those at risk or with established kidney disease who faced an uncertain future on dialysis.

When reading the medical files of WDNWPT members during the investigation, it is impossible to miss the distress and communication difficulties all encountered as the documented need for dialysis grew within an environment of crisis. Members often ‘refused’ or ‘declined’ clinical care and dialysis preparation, with several resisting hospitalisation or leaving care early despite being unwell, aware of the implications of palliation. Here, a thirty-six-year-old woman with concerns about ‘dislocation’ faces tremendous stress only two months before commencing dialysis.

- 2/97 Community Primary Health Care Service specialist nurse-trainers:  
*‘Her preferred option is renal transplant.’*
- 3/97 Renal Outpatient [seen in Emergency Department, short of breath; apparently had been refusing treatment in (community name)]:  
*‘The main point of contention regarding her refusal to accept RRT [renal replacement therapy] is relocating from (community name) to Alice Springs or even elsewhere and the subsequent fate of her children—three in number, the two elder ones are already petrol sniffers.’*
- 4/97 Renal Outpatient:  
*‘I fear that in spite of our best efforts, she does not know what is good for her.’*

She died four years later.

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Other entries describe the anger accompanying this resistance, as in this example where a sixty-two-year-old woman is strongly influenced by prior experience.

- 11/02 Inpatient: *'Clearly Mrs S is v. angry re renal diagnosis. Is in denial. Clearly has been advised re fistula/diagnosis etc. + is angry/in denial.'*
- 3/03 Inpatient: *'Doesn't seem to accept diagnosis of CKD [chronic kidney disease] and it has been difficult to broach the subject... She is familiar with RRT as her (husband's name) was maintained on HD [haemodialysis], but he died in (date).'*

Mrs S's husband had died on dialysis eighteen months earlier. In her case, she took just nine months to progress from first diagnosis of kidney disease to dialysis.

Descriptions such as these are representative of the routine *Yanangu* resistance to service delivery that required shifting to town for treatment. They also fit into the descriptions of poor communication and engagement described elsewhere,<sup>2</sup> and are linked by *Yanangu* to grief and the perpetuation of injury both in families and in the broader Indigenous community.

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# How Did WDNWPT Address the Situation and Reduce ‘Dislocation’?

WDNWPT’s focus was to develop and deliver a system of more appropriate support services and treatment options for *Yanangu* on dialysis, and to establish processes enabling it to operate as an effective, honest community advocate. During the lengthy two-year consultation period by the author, throughout the far-flung Western Desert communities that WDNWPT represents, the eleven-member *Yanangu* Governing Committee established a raft of interrelated initiatives. (For a fuller description of this groundwork, see Appendix 2 in the full report.)

## Lifeline Programs

The first programs to be implemented were *Lifeline* services. At present, two such Alice Springs-based programs operate concurrently:

- *Yanangu Advocacy Malpa (YAM)* provides social support and early intervention for members, predominantly through two dedicated, part-time workers supported by WDNWPT management. It promotes looking beyond dialysis, contributing to family and the wider Alice Springs community and to people regaining control over lives.
- *Return to Country* offers regular, brief planned visits home for those on dialysis, breaking prolonged absences from remote communities to maintain family and community life.



Return to Country

## Long-term Programs

By April 2004, one of two longer term strategic initiatives, *Going Home*, began to deliver dialysis training and treatment to members. It provides three-week treatment rotations in the 'Dialysis House' in the suburbs of Alice Springs, followed by a similar period spent in the 'Dialysis Room', based some 500 kilometres west, within the local Aboriginal community-controlled clinic at Kintore. Initially, WDNWPT funded two full-time specialist nurse-trainers who had responsibility for all dialysis delivery and training, and who worked closely with the clinical management teams at the RDU in Alice Springs. On the basis of positive, preliminary outcomes, the Northern Territory Department of Health and Community Services (NTDHCS) subsequently granted recurrent funds for these positions.

The other program known as *Bereavement*, an as yet unfinished process of grief resolution, was also initiated at this time.

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Dialysis (Purple) House, Alice Springs

Underpinning all WDNWPT programs are two complementary processes at work:

- *Yanangu Way*, the fundamental expression of *Yanangu* identity.
- *WDNWPT Way*, the attempt by WDNWPT to operationalise this identity.



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## The Yanangu Way

Since the inception of WDNWPT, the Yanangu Governing Committee has voiced the continuity of Yanangu ideas within their communities, and the advocacy work of particular individuals in the past. This was especially the case with the late Smithy Zimran Tjampitjinpa, 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*). As Yanangu, statesman, *Ingkata* (Pastor), and later as a dialysis patient, Zimran also shared the experiences of all 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 name<sup>3</sup> and a family group, and he always showed concern, sorrow for others.*

WDNWPT member

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.*

WDNWPT member

Through this shared identity of Yanangu belonging—of skin name and 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*), shows respect, a part of being human and definitely part of being Yanangu. It is Yanangu who best understand this (*kulintjaku*), knowing (*nintintjaku*) how they need to live as Yanangu, especially in maintaining their own wellbeing.

Yanangu Way offers an explanation as to why 'dislocation' is so disastrous. It shows, too, 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.

*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.*

Smithy Zimran Tjampitjinpa

Yanangu Way utilises 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.

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## The WDNWPT Way

The sustained process by which the organisation attempts to implement culturally appropriate solutions to meet the *Yanangu* expressions of wellbeing has become known as the *WDNWPT Way*. At its heart is *Yanangu* engagement in planning, decision-making, action and reflection, driven by regular committee and consumer meetings. Particular emphasis is placed upon accountability through relationships, including formal partnerships, and significant financial investment is made in order to hold regular meetings (\$40,000/yr). Such commitment has taken a considerable personal toll upon many senior *Yanangu* committee members, whose health has suffered as a result of their activism and dedication.

### Systematic monitoring

To better inform members and fundholders, systematic monitoring was used to document WDNWPT's activities and progress. WDNWPT invested \$100,000 over eighteen months to fund two researchers to carry out qualitative and quantitative monitoring of its activities. It was assisted in this by seeding grants from the CRAH and the NTDHCS, plus considerable in-kind expert support. A summary of WDNWPT program activities and associated monitoring results are provided in the following section. More extensive documentation of the *Yanangu* story and all WDNWPT activity, costs and outcomes can be found in the full report.

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Bush tucker trip:

Mantua Reid feeds Alan Snelson (WDNWPT renal nurse) his first witchetty

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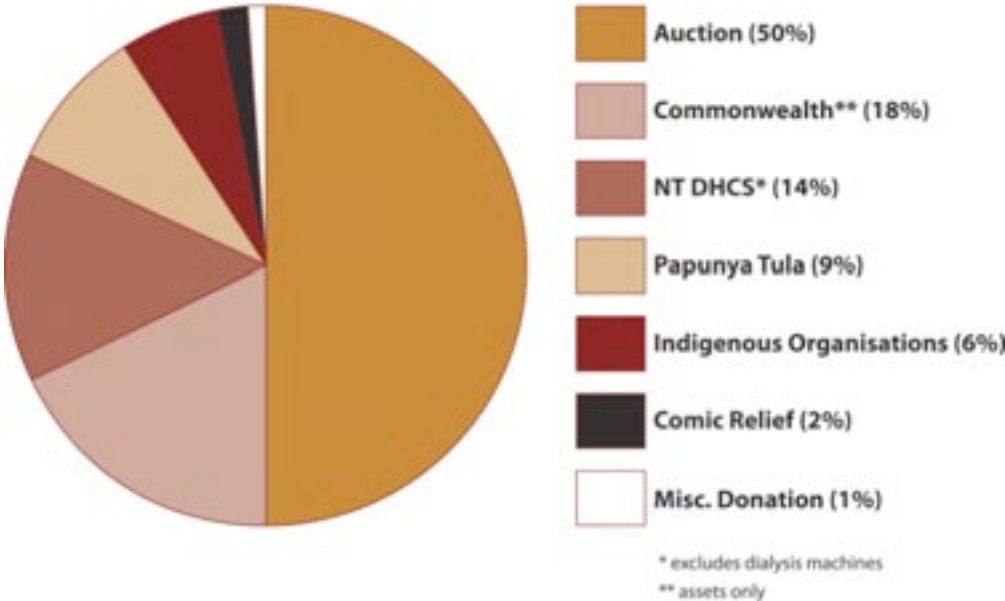
# The WDNWPT Programs: What Were the Actions and Outcomes?

Although \$1million sounds like a great deal of money, from the earliest stages it was evident that if *Yanangu* were to reap sustained benefit from the art auction, it would be necessary to build a case for recurrent, external government funding — in effect, a life after philanthropy. Realistically, WDNWPT believes philanthropic contribution will always be required to establish any innovative *Yanangu* solutions, and that WDNWPT itself will be required to persist in funding entire processes of planning, development and service inception for unknown periods, plus monitoring activity to present data about outcomes to stakeholders, particularly government.

### Self-determination

In the face of their hardship, *Yanangu* raised money to develop WDNWPT so as to address their own needs and aspirations through a range of strategically focused services. The resolve of the *Yanangu* members of WDNWPT to determine their own approach to renal service delivery is central to its success, as has been philanthropic financial autonomy. From April 2001 to November 2004, WDNWPT entirely funded the establishment and the management of all services. Since then it has continued to seek philanthropic and government funding to support *Yanangu* solutions. The following pie-chart gives a break down of the average contributions to WDNWPT from various funding sources over the past five years.

**Figure 1: Average % contributions to WDNWPT over past 5 years**



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## Lifeline Programs: *Yanagu Advocacy Malpa* and *Return to Country*

*Yanagu Advocacy Malpa* or YAM provides advocacy, early intervention and social support for members, ensuring access to basic entitlements. Diverse activities include practical pastoral and spiritual support to the ‘family on dialysis’, access to traditional healers (*ngangkari*), a successful Renal Choir, scooter painting, a patient consumer group and an Australian volunteers program.

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Western Desert Renal Choir

*Return to Country* offers free return travel home six times each year for all WDNWPT members, coordinated with routine dialysis in the RDU. It is aimed squarely at reinvigorating fundamental family networks — for *Yanagu* to remain healthy all family members must sustain 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.

## Outcomes

Both of these Lifeline Programs demonstrate quantifiable health and economic benefits to the acute care system, alongside the reinvigoration of *Yanangu* feelings of self-worth. *Yanangu* emphasise the vitality and optimism experienced by all (including staff), as family networks are re-established. WDNWPT members now have significantly better attendance at routine dialysis than their RDU counterparts. Hospitalisations associated with dialysis have reduced, resulting in actual cost-savings, with the cost/person/month of acute hospital care declining 28% from \$373 to \$268. In addition, dramatically fewer Royal Flying Doctor Service emergency evacuations are required from remote communities, as previous chaotic attempts by patients to stay with families resulted in missing routine dialysis causing acute illness.

## Costs

The cost of both Lifeline programs is \$110,000 per year:

- *YAM* costs \$60,000/year (32 hours/week + transport, plus \$40,000 in-kind).
- *Return to County* costs \$50,000/year (\$1908/person). WDNWPT is currently lobbying for regionalisation of this program.

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## Long-term Programs: *Going Home and Bereavement*

*Going Home* offers six weeks of (reverse) respite away from the Renal Dialysis Unit. A WDNWPT self-care trainer supports one to two members on dialysis for three weeks in a Dialysis House in suburban Alice Springs, followed by three weeks at Kintore in a Dialysis Room within the local clinic. A second team follows in rotation.



Children of dialysis patients play at Dialysis (Purple) House

Governing Committee members stressed the positive impact felt by families everywhere out bush, not just in Kintore, especially those who had been in town a long time:

*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.*

WDNWPT member

Dialysis in the community met an immediate need, but the machine's very presence allowed those 'coming behind', *Yanangu* with chronic kidney disease or young people as yet unaffected, to see, think about, even learn how to use it. One WDNWPT member, an experienced teacher, expressed this well:

*When they see the dialysis machine happening at Kintore, or when they get sick, maybe that'll make them think... 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.*

Any WDNWPT member on any renal replacement therapy can be supported. All participants are clinically reviewed by the nephrologist prior to entering the program, and Memoranda of Understanding between the Renal Dialysis Unit and Primary Health Care Services define roles and responsibilities. (Full details of *Going Home* dialysis delivery can be found in Section 5, Appendix 4 of the full report.)



Amy Nampitjinpa and family at her first dialysis in Country

The *Bereavement* program is a challenging negotiation process with the Northern Territory DHCS undertaken to address particular concerns raised by five WDNWPT families concerning the deaths of relatives on dialysis. Their expression of unfinished personal grief, the resultant injury to immediate family and the descriptions of systemic problems highlights a continuing negative impact upon those engaging with dialysis services. Acknowledging the complexity and distress in such a process, WDNWPT has invested time and money in explaining the importance of '*Yanangu Way*' — including customary gestures of atonement, intending to 'soothe 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 *Bereavement* progress has been achingly slow and incremental. The Governing Committee has continued to try to emphasise that it is showing proper concern (*alturringu*) to families in developing an approach that does not cause further injury. The current challenge for both WDNWPT and the NTDHCS is to acknowledge the differences while seeking enough common ground to make progress without recourse to an adversarial legal system.

Ultimately, however, only the families themselves will be able to say whether it has all been enough. Importantly, no other WDNWPT families have raised similar concerns since the advent of *Lifeline* programs.

## Outcomes

In September 2004 the first WDNWPT member successfully dialysed out bush, with limited government infrastructure support. A moving ceremony in Kintore, attended by *Yanangu* from across the region, celebrated the return of family members on dialysis and pride in achievement, mixed with sorrow for those who hadn't lived to see the day, yet hope for so many others.



Smithy Zimran's family talk at the opening of the Kintore Dialysis Room

Preliminary monitoring shows that over the first nine months a total of eighteen members received 144 dialyses safely, with 99.3 per cent attendance — significantly better than for other Indigenous patients in the RDU at Alice Springs. A preferred model of dialysis, it strongly supports the necessary rebuilding of family cohesion. Currently, WDNWPT provides the only training and services for community-based dialysis in Central Australia.

### **Mrs S: A success story**

Mrs S, the inpatient described on page 8, was ultimately brought into Alice Springs by her son for palliative care, refusing dialysis and unable to walk. She is now on her fifth journey home, and has taken her grandchildren back to visit her family's Country, south-east of Kintore. Although still marginalised in Alice Springs, living in a tin shed on the edge of a town camp, this is not her whole existence — she now has hope and opportunities once more.





Taking a short holiday

### Costs

For WDNWPT, the *Going Home* program had start-up costs of \$250,000, with recurrent costs of \$50,000/year. The NTDHCS contributes \$150,000/year for two self-care trainer wages recurrently (from 05/05), following a successful pilot in November 2004. WDNWPT has invested \$50,000 to establish the *Bereavement* program thus far.

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# Next Steps: What's Needed to Support Sustainability and Continuity of Programs?

In the first three and half years of WDNWPT's operation, which included the planning and implementation of all current services (cost \$470,000 approx.), no financial support from government was received. The initial independent, philanthropic finances provided *Yanangu* with a secure resource and an unusual opportunity to exert control by instituting improved health services to meet their own needs. By building on existing capacity (*Yanangu Way*), WDNWPT developed and consolidated regional networks to provide culturally safe kidney dialysis services with demonstrable positive benefits. However, the need to secure recurrent funding for programs that provide such clear health benefits for *Yanangu* — by allowing them to re-establish living relationships with Country, home and family — is a central element of the vision for the future.

To this end, alongside regional governance developments and systematic monitoring, WDNWPT undertook protracted negotiations with government stakeholders to engender serious funding responses. Again the initial philanthropy supported WDNWPT to develop sufficient organisational capacity to respond to all the recurring demands of bureaucratic institutions, and aspire to equality in partnership rather than subservience.

Maintaining this capacity is crucial but funding restraints have left the part-time manager to support all governance developments, informed debate and stakeholder advocacy as well as running day-to-day organisational services. Currently, the Commonwealth is discussing Shared Responsibility Agreements with WDNWPT, but the political and bureaucratic context of these seems most fluid and indeterminate.



Amy Nampitjinpa, Mrs Tolson and grandchildren in Country

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# Ongoing Work: What's Required?

Overwhelmingly, *Yanangu* identify the effects of 'dislocation' as the most serious 'impact' of well-intended mainstream health services. The subsequent challenge has been to identify the essential *Yanangu* and organisational characteristics that underpin WDNWPT's solutions and translate these for stakeholders, especially government. The latter must be encouraged to determine how best to meet stated responsibilities, while addressing uncertainties in its own capacity to respond to a different world-view.

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

1. To shift the primary financial responsibility for the provision of activities associated with the *Yanangu Way* from *Yanangu* communities to the health system.
2. To address deficiencies in health management quality along the pathway of care, including fundholder jurisdictions.
3. To ensure health service delivery meets expressed *Yanangu* needs.

Through their own efforts, *Yanangu* have debated issues, set the agenda, drawn-up and delivered a raft of programs — *Yanangu Advocacy Malpa*, *Return to Country*, *Going Home* and *Bereavement* — and developed a consumer forum linked to action and not simply to talk. Thereafter, they undertook an investigation that, although 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 entire process.

However, there is now an opportunity for governments, funding groups and individuals to consider new options to assist WDNWPT and the broader community to continue the innovative and successful programs they have put in place.

*This is why we're trying to 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.*

Marlene Nampitjinpa  
WDNWPT Executive Committee

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# Endnotes

1. Banskott Health Consulting 2003, Review of NT Department of Health & Community Services, unpub. report to NT Government, Darwin (Item 303). *Professor John Horvath undertook work, on behalf of the review, to review the current status of renal services in the NT. The work included site visits, formal and informal discussions, and a clinical consultation session... A key consideration was the provision of renal services closer to home* (Item 312).
2. J. Devitt & A. McMasters 1998, *Living on Medicine: A Cultural Study of End-stage Renal Disease among Aboriginal People*, IAD Press, Alice Springs; and A. Cass, A. Lowell, M. Christie, P. Snelling, M. Flack, B. Marrnganyin & I. Brown 2002, 'Sharing the True Stories: Improving Communication between Aboriginal Patients and Healthcare Workers', *Medical Journal of Australia*, 176:466–70.
3. Skin name is a system of patrimonial subsections, allocated at birth. Men (tj–), women (n–): *Tjapangati, Tjapanangka, Tjapaltjarri, Tjungurrayi, Tjampitjinpa, Tjangala, Tjakamarra, Tjupurrula*.

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# Want to Help?

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## Hey you readers!

## *Kulila!*

Western Desert Nganampa Walytja Palyantjaku Tjuṯaku Aboriginal Corporation (*'Making all our families well'*) is a non-government organisation working to bring people back 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 program supported by *'Volunteering Australia'*. 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 welcome ideas or assistance with fund-raising activities.

We are a registered charity and welcome tax-deductible donations.

If you think you can help or just want to ask 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**

**E: [wdnwpt@bigpond.net.au](mailto:wdnwpt@bigpond.net.au)**

**T: (08) 8953 0002**

**W: [www.wdnwpt.org.au](http://www.wdnwpt.org.au)**

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