

WESTERN DESERT DIALYSIS APPEAL

'Your place or mine' – dialysis in Central Australia



Introduction

This story is about the people of the Western Desert of Central Australia - Yanangu. It is about art, money, the devastation of kidney disease in our remote communities and in particular about one man's vision for a future.

Kumantjayi Zimran Tjampitjinpa was a remarkable Pintupi man who passed away in December 2000, having been a patient in the Alice Springs renal unit for almost 4 years. His vision and efforts laid the foundation for the Western Desert Dialysis Appeal to work to bring back people on dialysis to their own communities on treatment.

The Western Desert Dialysis Appeal (WDDA) is a non-government organisation entirely funded from the sale at auction of indigenous artworks from communities in the Western Desert.

The Region

Most of the 1200 Aboriginal people living in the remote, arid area west of Alice Springs live on parts of their traditional country in extended family outstations or on larger communities of a few hundred like Kiwirrkurra, 700 km west of Alice, across the WA border.



Pintupi, Luritja, Pitjantjatjara, Ngaanyatjarra and some Walpiri, Western Arrente and English are spoken in this area.

The people within this region refer to themselves as Yanangu.

The WDDA Kidney Committee has about fifteen Yanangu members who recognise their responsibilities to organisational membership through their cultural obligations of kinship, traditional country and 'tjukurrpa' (sometimes referred to as 'dreaming').



WDDA - Kidney Committee

Community Life Disrupted

In the late 1990's, many Western Desert people talked about the alarming number of their people needing kidney dialysis and the way treatment was being delivered. They talked about the disruption and loss to family and community life when patients and their families have to shift to the Alice Springs dialysis unit. Once in this regional unit, they live, and then inevitably die, so far away - haemodialysing "on the machine".

Senior men and women at the peak of their community influence, become chronically unwell and shift with their families for dialysis to Alice Springs - someone else's country. They are then asked to guarantee regular attendance at a clinical institution, almost another world, where they sense minimal respect and have very little control of their lives.

This was the experience and reality of Mr. Zimran, the man who brought this Western Desert Dialysis Appeal to a reality and whose legacy we are trying to fulfil.



Artworks auctioned to raise funds for the project

Astonishing Fundraising

In early 2000, an informal alliance of Aboriginal community representatives, local ALP politicians, art collectors and dealers planned an auction of donated artwork and four specially-commissioned paintings by men and women from Kiwirrkurra (WA) and Walungurru (Kintore) in the NT.

By the end of the year over \$1M had been raised, an astonishing sum, principally through a Sotheby's auction in Sydney. This money now finances the Western Desert Dialysis Appeal project, which aims to bring back individuals and their families from Alice Springs to dialyse on their home communities.

Neither the NT nor Federal governments has offered to match this money on a dollar for dollar or any other basis.

The Kiwirrkurra Men's Painting

Yanangu do not see their paintings as inanimate objects but as representations of life at various depths. The painting shown here is known as the Kiwirrkurra Men's Painting, one of the four specially-commissioned works. This painting shows Yanangu obligations of ngurra (traditional country), walytja (kinship) and tjukurpa (dreaming).



Kiwirrkurra Men's Painting: B. West Tjupurrula, B. Tjungurrayi, C. Wallabi Tjungurrayi, C. Ward Tjakamarra, J. Yungut Tjupurrula, K. Tjapangati, P. Tjungurrayi, T. Tjapanangka, W. Tjapangati. Painted November 1999. The painting shows designs associated with the soakage water site of Tjangimanta, just to the north-west of Kiwirrkurra community.

These three elements are all interrelated and through many complex processes of learning and understanding, form the basis of being Yanangu, a process commonly referred to as 'The Law'. This is the way that Mr. Zimran understood who he was and defined himself.

One artist explained that the stories accompanying the paintings when sold were only the surface. They are like an iceberg which displays only one tenth of its bulk above the sea level. Given the difficulty that many have in comprehending even the surface of a Yanangu world, it is not surprising that policies and programs directed at Yanangu fail to achieve their stated aims.

Community Power

The law is like a human being, it works with Aboriginal people A nangu. Anangu and the law is together, if that law is weakened, people get weakened and they feel they are weak because they have taken away the power in the community. That is the whole issue about community control under Aboriginal law .

Kumantjaji Zimran, 1997

It is also not surprising that the call for Aboriginal self-government in Central Australia is being led by the remote regions. Mr. Zimran tried to make those working closely with him understand the significance of Yanangu Law and take the message to other Australians. He was involved in many projects directed at the betterment of his people and developing an understanding between us all.

In 1998 Mr. Zimran became the chairperson and guiding hand for the Combined Aboriginal Nations of Central Australia (CANCA), a body committed to the recognition of Aboriginal law and self-government in Central Australia.

The vision he continually expressed was that of having those elements which define Yanangu being within their own control.

☉ Tingari Cycle



This family bush photo is of Karrkurrintinytja, a site south of Kintore in Mr. Zimran's country. This site is important in the cycle of the Tingari men whose travels are also indicated in the Kiwirrkurra painting.

This photo shows the elements that made Mr. Zimran and with which he strived to be united, not only for himself but for those who were also part of him. It shows his family (walytja), visiting country (ngurra) and viewing the dreaming (tjukurpa) of this place.

Songs were sung whilst travelling to reinforce attachment and children were instructed about the site. This is a happy photo which incorporates all the elements of being Yanangu which Mr Zimran missed so badly in Alice Springs.

☉ Renal Unit



The photo of the Alice Springs kidney dialysis unit makes a sad contrast. This is the space where patients from remote areas become entrapped. It is an indicator of the depth of this tragedy of illness and dislocation, that so many choose not to leave their family and country, never being offered the mainstream choices that are available to non-Aboriginal Australian citizens.

Mr. Zimran could not have his last wish granted, to die in his own community, because the appropriate services were non-existent.

☉ Kidney Services in Central Australia

Most regional kidney-related services are provided from Alice Springs. The town has 27,000 people, of whom 20% are Aboriginal and it lies exclusively in Arrente country. Anangu from the Pitjantjatjara lands in South Australia also look to the Alice for most services, as do those from the eastern Ngaanyatjarra lands in Western Australia. Currently (2002) there are about 80 people on haemodialysis in the Alice Springs renal unit which has enough space for 102.

Aboriginal people in the surrounding remote communities suffer end-stage renal disease about 30 times the national average. Individuals usually have type II sugar diabetes, high blood pressure and heart disease as well.

While Aboriginal people are only a quarter of the NT population, they make up about 90% of the people on dialysis. Most of these are women, who begin dialysis ten years earlier than others in Australia but enter the hospital system later, usually as a critically-ill patient. Though most people come from remote areas, only about 10% ever return home on dialysis compared to 38% of people nationally.





Kintore Women's Painting:

J. Napurrula, K. Nampitjinpa, N. Nungurrayi, N. Nungurrayi, N. Napurrula, P. Napanangka, T. Napurrula, T. Napaltjarri, W. Napaltjarri, Y. Nampitjinpa, Painted November 1999. It shows designs associated with the rock hole and soakage water sites of Marrapinti, Umari and Tjintjintjin.

This small group all use peritoneal dialysis (PD, or "the bag"). No-one from the project region has ever returned home to live on dialysis.

At the start of the project in April 2001, fourteen people from the Western Desert were on haemodialysis in Alice Springs, including members of three generations of one family. One year later, six of those fourteen people have passed away.

Most of those on dialysis in Alice Springs survive less than five years, compared to eight nationally. In the mid-1990's, people from the project region survived about 2 years! Discussions in one large primary health care service suggested that up to 25% chose palliation rather than dialysis away from their country.

◎ A World-Wide Story

Many Yanangu over 40 were born in the bush, and came with their families to government settlements between the 1960's to the 1980's (both voluntarily and involuntarily). They share with all other Aboriginal and Torres Strait Islander people the exposure to the spasms of change that have been directed by non-indigenous powers.

There is virtually no private economic activity apart from fine-art. Mineral royalties and welfare payments provide most of their income, placing them in the lowest 10% income nationally. Unemployment rates are above 90% (disguised by work-for-the dole schemes) and living costs are high - fuel is \$1.35/L, a small tin of Milo \$5 and bread more than \$3.

This picture of disease accompanying rapid lifestyle change, poverty and disadvantage is shared by indigenous populations world-wide.

◎ Project Strategies

Our central strategy rests on Mr. Zimran's philosophy that underlying control must rest in the hands of the people affected. To this end the Kidney Committee - both as informed individuals and a regional body - binds workers, members, communities and patients. There is a partnership formed when sitting down to understand the many issues surrounding dialysis from the mainstream perspectives of community, patient and provider. Problems, reflection and action require sharing between all stakeholders - both out bush and in town.

◎ Strategies

The strategies we are pursuing are:

- a parallel process of communicating the project issues and development between bush and town, family and home community
- the development of appropriate resources, including Yanangu themselves, to inform patients and families about treatment options
- a program which pays for six return flights per year per patient to their home community
- improving the living experiences of those currently on dialysis
- working with local and regional services to identify appropriate treatment options, including self-care dialysis on remote communities
- working with people about to enter dialysis
- incorporation

For further discussions, questions, making tax-deductible donations and asking about newsletters, contact:

kidney @ octa4.net.au

or WDDA, PO Box 562, Howard Springs, NT 0835; ph (08) 8983 3367