

# Haemodialysis service provision for remote patients in the Top End

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A report for the Uniting Church Northern Synod

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## Haemodialysis service provision for remote patients in the Top End: A report for the Uniting Church Northern Synod.

This report has been prepared by ARDS at the request of the Uniting Church Northern Synod, in order to update the Standing Committee in April 2018. ARDS were engaged to provide a report based on the following terms of reference:

- Provide a report on the current and proposed future state of dialysis provision in Aboriginal communities in the Top End of the NT;
- Where provision is being or is to be provided, what is the level of service;
- The extent of unmet need within the Top End of the NT.

While the focus of this report is on haemodialysis and the above terms of reference, to allow sufficient background the report also includes more general information regarding Chronic Kidney Disease in the NT and issues relating to CKD including management, treatment and prevention, different treatment modalities, and challenges regarding the provision of haemodialysis services in remote locations.

### Some key terms used throughout the report

- Aboriginal – this is used to refer to Aboriginal and Torres Strait Islander peoples across Australia.
- Chronic Kidney Disease (CKD) – is defined as kidney damage or reduced kidney function that lasts for longer than three months (Stumpers e Thomson, 2013);
- End-Stage Kidney Disease (ESKD) – is defined as the most severe form of CKD, and occurs when the remaining kidney function is insufficient to prevent death – Renal Replacement Therapy is required to prevent death (Stumpers e Thomson, 2013);
- Renal Replacement Therapy (RRT) – This includes haemodialysis and peritoneal dialysis, as well as kidney transplant (Stumpers e Thomson, 2013);
- Cultural Safety – this is based on the definition of Robyn Williams and stems from the work of Maori nurses in New Zealand. A culturally safe environment is one where people feel safe and secure in their identity, culture and community (Williams, 1999; Commissioner, 2011).

### Background

Across Australia Aboriginal and Torres Strait Islander peoples (hereafter referred to as Aboriginal) experience high rates of Chronic Disease, with higher morbidity and mortality rates, and a corresponding life-expectancy that remains around a decade less, when compared to the non-Indigenous population in Australia (Abs, 2010; **Overcoming Indigenous Disadvantage: Key Indicators 2016**, 2016). Chronic Kidney Disease (CKD) has a disproportionately large impact on Aboriginal people in Australia. CKD affects around 2% of Aboriginal people across the nation – it is 10 times more common than for non-Indigenous people, while the likelihood of hospitalisation and mortality due to reported CKD are around 5 times greater (Stumpers e Thomson, 2013). In the NT and the Top End, the picture of CKD is even more bleak, and its impacts are compounded by issues of remoteness, poverty, dislocation, and miscommunication (Hoy, 2014). In 2013 the prevalence of End Stage Kidney Disease (ESKD) was estimated at 11 per 1000 Aboriginal people in the NT (0.9 per 1000 non-Indigenous), with 71% of patients under this criteria receiving Renal Replacement Therapy (RRT) (Li *et al.*, 2018).

The predominant RRT modality is nurse assisted haemodialysis in a centralised 'hub', namely in Darwin, Alice Springs or Katherine. This treatment requires 4-6 hours three times every week, and the centralised location results in patients relocating to a major town, away from family with limited supports, where they can undertake life-continuing treatment. This results in them missing important funeral, ceremony and familial obligations in and around their home community, and experiencing additional stressors that come from living in major town (Devitt e Mcmasters, 1998a). ESKD is far more common in remote areas, where the majority of Aboriginal people in the NT live, and the numbers of people undergoing RRT continue to increase, placing additional stress on the service provision for patients requiring RRT (You *et al.*, 2015; You *et al.*, 2017).

## Methods

Due to the nature of this report and the short timeframe, the methods used are opportunistic rather than comprehensive. Two key activities formed the basis of the information gathered in this report: semi-formal interviews with key informants; and a targeted review of the literature to identify peer reviewed and grey literature regarding End-Stage Kidney Disease and Renal Replacement Therapies amongst Aboriginal people in Australia and/or within the Northern Territory.

### *Interviews with key informants*

Key informants included patients, carers, researchers, and staff and organisations broadly involved in the provision of renal services in the NT including government and Community Controlled organisations.

Interviews with key informants were undertaken primarily to identify the current and future service provision of renal replacement therapies for remote Top End patients. These interviews also provided valuable background information regarding the history and broader political sphere regarding renal service delivery in the NT, as well as unmet needs.

### *Review of the literature*

This included grey literature, government reports and official statistics. Sources for conducting the literature review included Google search, google scholar, Indigenous Health Infonet, and literature referred to by key informants.

The review of the literature was undertaken primarily to identify data regarding historic, current and predicted levels of CKD and ESKD for Aboriginal people in the Top End, and to inform regarding areas of unmet need.

## What is Kidney failure?

Our kidneys play an important role in the function of our body through four main mechanisms: regulating the balance of water and mineral content, the excretion of water soluble waste products, hormone production, and regulating our blood pressure. The key functional component of kidneys is the nephron, which acts a bit like a filter and is responsible for the regulation of water and mineral content and excretion of waste, with around 1 million nephrons in a human kidney; excess and waste products are excreted as urine (Stumpers e Thomson, 2013).

Kidney disease results when this function is impaired. CKD occurs through repeated and/or ongoing damage to the nephrons, while ESKD occurs when our kidneys are no longer able to function adequately to maintain life, requiring renal replacement therapy to support life (Stumpers e Thomson, 2013).

## The situation for Aboriginal people in the NT

Data is generally readily available for the NT as a whole, with a breakdown for Aboriginal vs non-Indigenous and often for remote vs non-remote. Data for the Top End or specific regions is only sometimes available, and so data has been used for Aboriginal people in the NT unless specified otherwise.

As noted above, the occurrence of ESKD for Aboriginal people in the NT is much higher than in the non-Indigenous population, both within the NT, and Australia as a whole. For Aboriginal people in remote areas (when compared to Aboriginal people in non-remote areas), they are more likely to have ESKD, more likely to be women, and have a younger age at diagnosis (Hoy *et al.*, 2012; Hoy, 2014).

The leading causes of CKD in Aboriginal people in remote Australia are diabetes, glomerulonephritis (inflammation of the kidney, often secondary to chronic high blood pressure in this context), and IgA nephropathy (immune mediated kidney damage following infection). A review of biopsy results also notably identified the preponderance of enlarged kidneys for Aboriginal people in remote areas – the enlarged kidneys thought to be in response to lower numbers of nephrons, the functional part of the kidney (Hoy *et al.*, 2012). While the reasons for very high rates of ESKD in remote Aboriginal people are still not well understood the lower numbers of nephrons, which is likely caused at least in part by low birth weight, is thought to contribute to a greater susceptibility to kidney disease (Hoy *et al.*, 2012; Hoy *et al.*, 2016).

### *Socio-environmental factors*

The persistent disadvantage facing Aboriginal people in remote Australia are also likely contributors, with poverty, crowded housing, lower levels of education and unemployment sitting alongside poor nutrition and smoking as part of the everyday disadvantage facing Aboriginal people in remote areas (Hoy, 2014; **Overcoming Indigenous Disadvantage: Key Indicators 2016**, 2016).

## End-Stage Kidney Disease

### *High incidence and increasing prevalence of ESKD*

Data is generally only available to 2014.

Rates of ESKD amongst Aboriginal people in the NT are very high, with the demand for RRT doubling every 15 years (You *et al.*, 2017). Incidence rates of ESKD in the 1990's were reported as 15-30 times higher in Aboriginal than in non-Indigenous patients across Australia. From 2007 to 2011 there were an average 60 new cases per year and through 2010 to 2014 there were an average of 76 new cases per year amongst Aboriginal people in the NT (Hoy, 2014; Registry, 2016). In 2014 555 Aboriginal people in the NT were accessing RRT, 4 times the prevalence of Aboriginal people across Australia (Registry, 2016).

The age-adjusted incidence for Aboriginal people in the NT is estimated to be around 12 times that of the general Australian rate – Aboriginal people in remote NT tend to get ESKD at a younger age than the remainder of the Australian population (Hoy, 2014).

These rates are believed to underestimate the true burden of ESKD, with around 75% of patients undergoing RRT registered on the national database with the Australia and New Zealand Dialysis and Transplant Registry (Registry, 2016), from which most data for ESKD and RRT are obtained (You *et al.*, 2015). The true burden of disease is likely to be around 33% higher than reported above, with a study by Li *et al.* published in 2018 used data matching from multiple sources to identify that as at 31<sup>st</sup> December 2013 there were 682 Aboriginal people in the NT with ESKD (Li *et al.*, 2018).

Survival upon commencement of RRT has increased in the NT from a median of 4.5 years in 2005 to 6 years in 2009 (You *et al.*, 2015).

The proportion of Aboriginal patients in the NT with ESKD who were receiving RRT is estimated at around 71% (Li *et al.*, 2018).

No Aboriginal people in the NT received a kidney transplant during the 2010 to 2014 period (Registry, 2016).

The number of patients in the NT accessing Palliative Care services for end of life care has increased dramatically from just 7% of ESKD patients in 2001, to 47% (61 patients) in 2012 (You *et al.*, 2015).

From 2001 to 2012 there were 1247 people who commenced RRT in the NT (Aboriginal and non-Indigenous), based on hospital data. Approximately 75% of these were registered on the national database – this is the data that many publications will use when reporting on ESKD (Li *et al.*, 2018). The number of cases of Aboriginal people in the NT undergoing RRT increased from 430 in 2010 to 555 in 2014, around 3 times the prevalence of Aboriginal people throughout Australia (Registry, 2016).

### *Looking ahead*

Overlying all of this is that there continues to be a continuing increase in the number of remote Aboriginal patients with ESKD, with the demand for RRT doubling every 15 years, although this rate of increase may be starting to slow and into the future remains subject to influences from policy changes (You *et al.*, 2017). Part of the increase is explained by an increasing population, increasing life-expectancy for the overall remote Aboriginal population in the NT, as well as by increased survival following commencement of RRT (You *et al.*, 2015; Hoy *et al.*, 2016). If the current trends were to continue, the demand for Haemodialysis would increase around 5% per year and reach around 100 000 treatments per year by 2023 (compared to around 60 000 treatments in 2014) (You *et al.*, 2015). This demand can be mitigated by improving prevention of ESKD, improving transplant rates, and increasing the rate of self-care (You *et al.*, 2017).

## **Treatment modalities**

*Nurse Assisted Haemodialysis (HD)* – this is the most common form of renal replacement therapy, usually undertaken in a dedicated renal unit where specially trained renal nurses will provide the Haemodialysis. It is also the most expensive RRT to administer, because of the requirement for specialist nursing staff, with each HD chair capable of providing dialysis for up to four patients, who must undergo HD 3 times each week.

Nationally this accounts for 80% of Aboriginal patients receiving RRT (40% for non-Indigenous) (Registry, 2016).

Nurse Assisted haemodialysis in remote communities – Regional and remote dialysis units are only available to dialyse patients who are stable and healthy – abnormal clinical findings and concurrent health conditions increase the risk of complications from dialysis and currently require treatment in a higher level facility (in Darwin or Alice Springs). Logistical, financial and practical considerations have historically limited the application of this in smaller and more remote centres.

*Self-Care Haemodialysis* – This is self-administered, usually by a patient and/or family member and can be undertaken anywhere with a dialysis chair and appropriate associated facilities. This is possible both at home, and in a dedicated renal ready room within communities. It requires appropriate training to ensure the patient and family member have the required skills, as well as to ensure a very high standard of hygiene and the maintenance of sterile materials and immediate surrounds. It also requires access to relatively large volumes of sterile water. While this is a good option for allowing patients to dialyse within their home community, many barriers have limited the number of patients who are able to safely self-dialyse. Included amongst the barriers for remote Aboriginal patients are differences in language and worldview, low baseline health literacy, cultural fear and implications for family members assisting if something goes wrong or a patient dies, as

well as physical limitations of reduced visibility and mobility for patients affected by comorbidities such as diabetes (Vass *et al.*, 2011).

Nationally this accounts for 7% of Aboriginal patients receiving RRT (13% for non-Indigenous) (Registry, 2016).

*Peritoneal Dialysis (PD)* – This is also self-administered and involves a four times daily regime of fluid transfer into and out of the peritoneal cavity (the free space within the abdomen). This can be undertaken anywhere with a clean space, and allows people to be mobile and move between communities. It does require some training and skill development to be able to perform PD, and carries an ongoing risk of peritonitis (infection of the peritoneal cavity) which requires hospital management and IV antibiotics. Similar barriers to those for self-care dialysis have limited the number of patients who have taken this route. Additionally, patients usually end up requiring haemodialysis, so PD allows the patient to stay at home and retain mobility before ultimately requiring HD.

Nationally this accounts for 8% of Aboriginal patients receiving RRT (11% for non-Indigenous) (Registry, 2016).

*Kidney Transplant* – this is ultimately the most effective treatment for ESKD, improving both quality of life and life expectancy. Transplant rates for Aboriginal people in Australia are low compared to the non-Indigenous population. Undergoing a transplant is a major procedure and requires a comprehensive clinical workup and investigation, as well as thorough education and patient understanding. Comorbidities, miscommunication, non-referral and remoteness are also identified barriers to transplant. Australia has a low rate of organ donation, and successful organ donation requires compatible blood and immune profiles of donor and recipient – there is a lower compatibility rate for Aboriginal people compared to non-Indigenous.

Nationally this accounts for 12% of Aboriginal patients receiving RRT (48% for non-Indigenous) (Registry, 2016).

### **Community preferences regarding RRT**

The sociocultural impacts of relocation in order to undertake haemodialysis have been explored in a number of research papers and forums, and the unequivocal response from Aboriginal people in remote communities, both those with ESKD and their carers, families and community members, is that the strong preference is for dialysis on country, in or close to a person's home community (Hughes *et al.*, 2017).

*"The best thing is to be able to do dialysis in our home community, surrounded by our family."*  
Aboriginal dialysis patient from Arnhem Land.

## **Current Provision of Renal Replacement Therapies for remote patients in the Top End.**

The predominant model of care for patients in the Top End with ESKD revolves around central haemodialysis hubs in the Darwin region.

### *Urban*

Darwin region: Nurse assisted haemodialysis facilities exist on the renal inpatient ward at Royal Darwin Hospital, Nightcliff and Palmerston.

Royal Darwin Hospital – 6 HD chairs alongside the 14 bed ward allow acute care in a tertiary health facility. Services include clinical preparation for dialysis, clinical preparation for transplant, patient education, catheter insertion and acute care and dialysis for ESKD patients with complex needs and acute concurrent illness.

Nightcliff – This 25 chair facility can provide nurse assisted haemodialysis for up to 100 patients. It is the premier dialysis facility in the NT, and is where the facilities at Palmerston, Katherine and Wurrumiyanga are run from. Nightcliff renal unit also provides training for peritoneal dialysis and self-care dialysis. It also has capacity for one respite/ holiday/ visitor patient per week, although demand is high in the dry season and advance bookings are essential.

Palmerston – This 8 chair facility provides nurse assisted dialysis for up to 32 patients.

### *Regional*

Katherine – This is a 16 chair renal unit run jointly by NTG and Fresenius medical care.

### *Remote*

Nguiu/ Wurrumiyanga (Bathurst Island) – This is a seven chair unit run by NTG that was originally built for use by self-care patients, however it receives staff from Nightcliff renal unit on a fly-in fly-out basis each week, so its main focus is now on nurse assisted haemodialysis, with self-care dialysis still an option but now the exception rather than the norm. The Tiwi renal unit has a long history having initially commenced in 1999.

Yirrkala – Miwatj Health in partnership with Western Desert Dialysis (WDNWPT, The Purple House) have setup a facility with 2 chairs that can provide nurse assisted dialysis for up to 6 patients. WDNWPT provide nursing support. This option is available for resident dialysis, although at the time of research only 2 patients were currently accessing this option. There is also one self-dialysis chair available within the hospital in Nhulunbuy.

Groote Eylandt – Western Desert Dialysis have partnered with Miwatj Health and the NTG to provide a nurse-assisted haemodialysis service on Groote Eylandt in Angurugu. This uses the existing renal ready room with 2 chairs, although nurse assisted dialysis must be strictly kept separate from the existing self-care haemodialysis patient who utilises this facility.

Galiwin'ku – Miwatj Health and Western Desert Dialysis partnered in 2017 to provide temporary nurse assisted haemodialysis at Galiwin'ku during the funeral for Dr G Yunupingu. This utilised the existing renal ready room and haemodialysis chairs which are otherwise designated for self-care patients only, under agreement with the NTG. Miwatj Health are currently exploring opportunities to continue this on a regular or permanent basis.

Lajamanu – 2 chair facility operating since 2013 providing nurse assisted HD for patients, though this is currently limited to a reverse respite model allowing patients to spend up to 8 weeks at a time on dialysis in Lajamanu. Western Desert Dialysis are planning to upgrade this facility to 4 chairs by July 2018.

Other communities/ opportunities – Western Desert Dialysis are currently looking to commence a nurse assisted haemodialysis service in Kalkarindji, which is scheduled to open in 2018.

In each of the communities where Western Desert Dialysis are providing nurse assisted HD service, a community and patient led approach is taken to determine the level of service that can be provided, within the scope of allowing everyone the opportunity to be able to receive some dialysis in their home community. For example at Lajamanu the patients and community decided that it was important for all patients to be able to spend time at home, so patients can have 8 weeks at home at a time.

Self-Care dialysis is available in many of the larger remote Top End communities, with renal ready rooms listed on the NT renal services website as including: Borrooloola, Ngukurr, Angurugu, Yirrkala, Nhulunbuy, Galiwin'ku, Milingimbi, Ramingining, Maningrida, Gunbalanya, Barunga, Nguiu and Wadeye, Kalkirindji (Home and community self-care dialysis therapies: remote community dialysis facilities). However as noted previously there remains a low uptake of this option, only around 3% of ESKD patients undergoing RRT in the NT (You *et al.*, 2015; Registry, 2016). These renal ready rooms may be attached to the clinic, or in a separate building/ demountable, with appropriate plumbing, power and hygiene facilities. The Haemodialysis machines however are unable to remain on community if they are not being used and so are returned to Darwin and relocated back to these communities when a patient returns for self-dialysis.

Peritoneal Dialysis remains an option for self-dialysis in one's home community, and can be done anywhere including on homelands, however as noted above it also has a low uptake amongst patients in the NT (around 10%) (You *et al.*, 2015; Registry, 2016).

Mobile Haemodialysis – The purple truck is a mobile HD unit that travels to remote communities, predominantly in central Australia, to allow people to have some time dialysing on country. This is run by Western Desert Dialysis (aka the Purple House). There is another bus that was built by the NTG but which has largely been unused for the last 7 years, and Western Desert Dialysis are trying to negotiate a pathway to be able to utilise this as a second 'Purple Bus'.

Transplant – As noted above, just 12% of Aboriginal patients with ESKD across Australia receive a transplant, a dramatic difference to the 48% of Non-Indigenous patients, while in the NT no Aboriginal patients received a transplant in the five year period from 2010-2014 (Registry, 2016).

### **The broader political landscape regarding dialysis for remote Aboriginal people**

Interest, awareness and understanding of CKD amongst Aboriginal people in remote NT has grown from fledgling interest in the 1980's, to a developing understanding and service provision in the 1990's including the commencement of a dialysis facility on the Tiwi islands in 1999. The NTG preference has been to focus on centralised dialysis and the support of peritoneal dialysis and self-care HD that people can undertake independently at home.

However PD and self-care HD have had low uptake in remote NT, with a number of strong barriers influencing this including physical limitations, issues of communication, health literacy and education, as well as significant cultural barriers such as issues of blame and sorcery for family members involved in or responsible for a patient's care (Lowell, 1998; Devitt e Mcmasters, 1998a; Cass *et al.*, 2002; Vass *et al.*, 2011; Lowell *et al.*, 2012).

The strong preference for remote Aboriginal people is for dialysis to be provided on country or in a nearby community, reducing isolation and allowing ongoing strong connections to country, kin,

funerals and ceremonies and fulfilling cultural obligations, as well as being able to continue to be active community leaders (Devitt e Mcmasters, 1998b; Hughes *et al.*, 2017).

Concern amongst community members about the impact of senior elders being forced to relocate to Alice Springs for life-maintaining dialysis ultimately led to the development of Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT), aka Purple House/ Western Desert Dialysis, as a community controlled health organisation to provide nurse assisted HD in remote communities.

WDNWPT have been preeminent as the community controlled organisation working towards the provision of remote nurse assisted haemodialysis, both permanent and reverse respite/ holiday dialysis, as well as providing support services and a culturally safe dialysis facility in Alice Springs. They've been successful in setting up nurse assisted HD in numerous permanent sites across central Australia and into the Top End, plus a mobile service and support services in Alice Springs and Darwin, often in partnership with local Aboriginal community controlled organisations.

Miwatj Health are also now playing a key role in East Arnhem Land and Groote Eylandt, actively delivering some NAHD services in partnership with WDNWPT – Miwatj contribute the resources and facilities and WDNWPT contribute the service provision (the renal nurses). In some locations the NTG have also contributed by allowing the use of existing renal ready rooms/ self-care dialysis chairs (although kept strictly separate from any self-care dialysis patients). In East Arnhem Land, much of the support and finance has come from Aboriginal organisations, including ALPA, Gumatj Association and Anindilyakwa Land Council.

The federal system of government and particularly the designation of responsibility for health falling under the jurisdiction of state and territory governments in Australia is also a relevant topic for consideration. The NTG preference for a more centralised dialysis service with remote self-care has limited the scope for NTG funds being directed to nurse assisted HD in remote communities, while the federal government have somewhat more limited scope with what they are able to fund directly. The Federal government have supported financially the construction of 'renal ready' rooms which are designated for dialysis, however the expectation is that the NTG would cover ongoing costs for dialysis but the NTG have continued to prefer the self-care model.

### **New Medicare rebate for remote nurse assisted haemodialysis**

Nurse assisted haemodialysis is expensive, requiring half a day of hospital care 3 days per week, the equivalent of 75 full days hospital care per year per patient. Costs for a private dialysis service are in the realm of \$450 - \$900 in Australia per session (Australian HD travel). One pathway for ongoing Federal government assistance was highlighted in The Medicare Benefits Schedule Review commencing in 2015. It has recommended the creation of a new MBS item to support access to assisted haemodialysis in remote areas (**Report from the Renal Clinical Committee, December 2016**, 2016). This recommendation is still under consideration, although initial suggestions have been for a billing amount of \$100 per session, far less than the cost of dialysis.

## Unmet need

This section of the report includes relevant information regarding deficiencies in the present system – these deficiencies comprise a large component of what can be considered the ‘unmet need’.

### *Dialysis on country - nurse assisted haemodialysis in remote community's*

Patient voices consistently highlight the negative impacts of relocation to a large urban centre to access life-continuing RRT. People are removed from their strong social and cultural networks, from kin, from funerals, from family, from cultural and ceremonial obligations, not to mention the strong connection that Aboriginal people share with country (Devitt e McMasters, 1998b; Hughes *et al.*, 2017).

*"There is lots of worry being in town for Dialysis. We miss out on our homeland food, lifestyle, hunting, family, and we miss funerals and ceremonies which are important for us."*

Carer of Aboriginal patient from Arnhem Land.

The fact that many Aboriginal people with CKD from remote areas are elders and senior leaders of their community only exacerbates these issues: it negatively impacts both the individual and the family and community (Devitt e McMasters, 1998b). Not only are people removed from these close connections, but they are also exposed to ‘humbug’ associated with life in a large urban centre – lots of people, alcohol, gambling, money, violence, which are all generally more strongly present than in remote communities.

Housing upon relocation is also an important issue – patients and their families are often hindered by “limited, restrictive and expensive accommodation”, such as in Aboriginal hostels and public housing, which are often not able to accommodate supportive family members. Additionally sometimes accommodation options are not available or are deemed not suitable and the patient will resort to living in the long-grass (Hughes *et al.*, 2017).

The strong preference remains for people to be able to dialyse at their home community, where this is not an option then being in a large city living with close family is a compromise, but living on your own is undesirable, and there is a perception that those people from remote communities living on their own on dialysis in a large city have the shortest life-expectancy (Hughes *et al.*, 2017).

### *Communication, cultural safety and the biomedical focus of the health system*

A frequently identified deficiency continues to be around issues of communication.

Miscommunication is well document for renal patients from remote areas, but remains frequently underestimated by medical professionals and exacerbated by poor recognition of the extent of miscommunication (Cass *et al.*, 2002). This impacts important diagnosis and treatment discussions, as well as attempts at patient education and efforts to enable self-management, resulting in a lack of meaningful information provided to patients (Lowell, 1998; Lowell *et al.*, 2012).

Patients also identify a lack of understanding of ways that they can provide feedback regarding the system, and so remain unable to positively influence the way that services are provided (Hughes *et al.*, 2017).

Another issue frequently identified in patient responses is the strong biomedical focus of the health system and the often complete lack of cultural safety when accessing mainstream services in large urban centres (Lowell, 1998). These are separate but related issues, which compound each other. The system is foreign and insensitive, there are very few people in the workforce who are Aboriginal and share some of the cultural, worldview and language features of Aboriginal patients from remote areas (Vass *et al.*, 2011), and there is little in the way of overt efforts to create a culturally safe environment.

While there are strong arguments to be made that it is a clinical service being provided, our improved understanding of the holistic nature of health, particularly for Aboriginal people, and the

benefits and need for culturally safe health services, suggests that unless RRT services are holistic, culturally safe, and deliver meaningful information and effective communication, that clinical service will be ineffective and a poor use of resources.

#### *Self-care and Transplant – understanding the barriers and improving access*

Kidney transplant is the preferred form of Renal Replacement therapy, however across the country fewer Aboriginal patients than non-Indigenous receive a kidney transplant, and additionally those that do receive a transplant have worse health outcomes than their non-Indigenous counterparts (Rogers *et al.*, 2006). There remains scope to improve our understanding of the reasons for poorer health outcomes for transplant recipients and of the barriers to kidney transplant for Aboriginal patients.

Similarly the potential benefits of self-care options with regards to being able to remain on country highlight that we need to at the very least improve our understanding of the barriers to self-care, as even a modest increase in the number of Aboriginal people able to undertake self-care dialysis could have significant benefits for keeping people on country and improved individual and community wellbeing. While it remains a less preferred or inappropriate option for many, it should continue to be offered as one of the various Renal Replacement Therapies.

Additionally some data suggest that up to 29% of remote Aboriginal patients with ESKD do not receive RRT (Li *et al.*, 2018). It remains somewhat unclear if this represents an unmet need with regard to some patients not taking the option to proceed with RRT, and whether in particular the availability of nurse assisted haemodialysis on country would influence the decision making process (Li *et al.*, 2018).

## **Costs**

The cost of providing renal services is expensive, particularly in the NT where our small population, large geographical area and the high proportion of people in very remote communities provide a massive financial and logistical burden - costs which are largely borne by NT Department of Health. Nurse assisted Haemodialysis accounts for around half the hospital admissions each year in the NT, with the equivalent of around 75 full days of hospital admission per RRT patient per year for dialysis alone.

Nurse assisted haemodialysis is expensive to administer, as indicated by the private sector HD cost of \$450-900 per session nationally, while self-care haemodialysis and peritoneal dialysis are much less expensive and allow the possibility of treatment on country.

Remote nurse assisted haemodialysis is likely to be more directly expensive than urban and regional dialysis, however this may look different once consideration is given to less direct costs such as those of relocation, providing housing and other supports in urban areas, as well as costs of missed treatment and subsequent hospital admissions, alongside the sociocultural cost of relocating people many hundreds of kilometres away, essentially to a foreign country, to receive life-continuing treatment. A Menzies study led by Gillian Gorham and Alan Cass is currently being undertaken to look at a broad range of costs of different dialysis models of care.

There are also great logistical challenges to being able to support nurse assisted dialysis in remote communities including staffing, housing, facilities and supports, which generally requires a critical mass to be viable – Western Desert Dialysis have been able to make this feasible with 2 chairs and 4 patients for one nurse.

## **Prevention should be the predominant long-term focus**

Underlying all this discussion of treatment for patients with ESKD, the issue of prevention must continue to be strongly promoted. "Prevention is better than a cure" is a popular phrase for good reason. The cost of preventing illness, particularly one such as CKD which has such major implications for treatment, is invariably a fraction of the cost of treatment.

Primary prevention focuses on prevention of illness before its onset, so the primary prevention approach necessarily involves housing, education, employment and health literacy alongside a strong primary healthcare system which is both clinically efficient and culturally safe. It also includes a necessary focus on efforts to reduce chronic disease more broadly, and specifically focussing on reducing smoking, poor nutrition, and improving maternal wellbeing to maximise foetal nutrition, growth and birthweight which are strong predictors of future chronic disease. Primary prevention is a long-term focus.

*"For me I have some hope. I feel hopelessness at having this terminal illness, but I also have hope because I can teach our young people about health and how to prevent this sickness."*

Aboriginal patient from Arnhem Land

Secondary prevention focuses on prevention of and mitigation of CKD from the early signs of both CKD and contributing comorbidities such as diabetes, hypertension and chronic infection. Well reimbursed MBS items such as the adult health check, the free access of medicines in remote areas, a focus on clinical quality improvement, and where existent the presence of strong community controlled health organisations all play an important role in secondary prevention and should continue to be supported (Hoy, 2014).

The reality of finite health funding and a population approach to health necessitate that prevention should be awarded due importance within the health budget – one of the great challenges in health is to deliver such a strong focus on prevention while not detracting from the care of existing patients.

## **Conclusion**

It may not be an exaggeration to say that moving to the city to undertake dialysis allows life-continuing treatment, but removes people from all that is important in life.....

The impact of CKD for remote Aboriginal populations in the NT is massive, and arguably the greatest health concern for this population. Relocation to a major urban or regional centre has massive sociocultural impact on patients, families and communities. While self-care options are available, the reality is that these have not had a high rate of uptake amongst remote Aboriginal patients in the NT. We should be responding to the emphatic voices of Aboriginal people and, where possible, striving to provide modalities of RRT to Aboriginal people on country, specifically nurse assisted haemodialysis. Great financial, practical and logistic challenges exist to make this a reality, but in the present era of patient centred care and the focus on culturally responsive healthcare we should be able to follow the lead of Western Desert Dialysis to "have our treatment on our own country" (Hughes *et al.*, 2017).

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