22 February 2016

Hon David Tollner MP
Treasurer
Department of Treasury & Finance
GPO Box 3146
Darwin NT 0801

Dear Treasurer,

Kidney Health Australia (KHA) is the national peak body dedicated to helping people with kidney disease, with a view to improving their health outcomes and quality of life, and that of their families and carers. We operate under four key pillars of education, advocacy, research and support. KHA has a strong history of advocating for health initiatives to reduce the community's risk of kidney disease, as well to improve treatment and care for patients, in a realistic and cost effective way.

Kidney disease is a disease that affects 1.7 million Australians – a striking 1 in 10 over the age of 18 years have at least one clinical sign of chronic kidney disease (CKD). KHA estimates that one in three Australians are at increased risk of developing CKD. We are closely engaged with our consumers and those who are affected by kidney related illness.

To that end, the initiatives proposed here will help ease the burden of kidney disease for both patients and carers. Receiving assistance to maintain a home dialysis routine through adequate electricity subsidy levels, and having the ability to travel interstate when the need arises, are two issues our consumer committees have told us would go a long way in improving their quality of life.

Therefore, we have attached two policy papers for your consideration. The first relates to out of pocket electricity expenses for those on home dialysis, and the second is a proposal for the adoption and replication of an "Enable" visa scheme for interstate travel for those on dialysis. Such a scheme is proven, already successfully operating in NSW and the ACT.

In the case of these two initiatives, the cost to government is small, especially in comparison to the overall size of the health budget. These two schemes would go a long way in removing barriers and improving their quality of life, and in the case of electricity rebates, can encourage the use of more cost effective methods of dialysis.

The two proposals as attached do not represent a full list of the issues that need attention in the kidney community, however they represent two of the most relevant and targeted investments that could be made in the forthcoming state budget.

Yours sincerely,

Anne Wilson
CEO & Managing Director

Prevent, Detect, Support.
The Impact of Increased Power Costs on Home Haemodialysis
Northern Territory

1. Purpose
The purpose of this discussion paper is to illustrate the potential impact of increased power costs on the number of people choosing to undertake or remain using home haemodialysis within the Northern Territory (NT).

2. Background
The Northern Territory has the highest prevalence rate of dialysis patients in Australia.¹ This is comprised of a significant number of Aboriginal and Torres Strait Islander renal patients, with a rate of 743 per million population (pmp). The treatment option most utilised is haemodialysis, through stand-alone renal units in Darwin, Katherine, Tennant Creek, and Alice Springs or satellite centres in remote communities offering closer to home nurse-lead or self-dialysis models of care.

Renal units and satellite centres in the Northern Territory are operated by the Northern Territory Government or in some cases an Aboriginal Community Controlled Health Service.

The Northern Territory has a small number of renal patients that undertake home haemodialysis. A combination of remoteness, socioeconomic factors, physician preferences and availability of local training facilities are all likely reasons for differences in dialysis treatment location rates.

3. Modality & Costs in Northern Territory
In cases of home haemodialysis patients, increases in the cost of electricity contribute significantly to a situation where they face costs of up to approximately $870 per annum.

Appendix B provides a Home Dialysis Power Usage Analysis for Northern Territory for a 6 hour dialysis session and a 9 hour nocturnal dialysis session. It finds that there is annual power cost of $1008.90 for a 9 hour nocturnal dialysis. While there is an annual dialysis rebate of $140, there is a differential shortfall of $868.90 per annum to the patient/household for home haemodialysis.

While, the Northern Territory has a low rate of home haemodialysis there is a real out of pocket electricity cost to undertake dialysis at home.

4. Modality & Savings

Figures 1 illustrates the number (expressed as a %) of Northern Territory dialysis patients by mode of dialysis between 2004 and 2013 (Source – ANZDATA).

![Northern Territory number of people on each modality of dialysis](image)

**Figure 1 – Number of NT patients undergoing dialysis by mode**

Points worth noting from Figure 1 includes:

- The total number of dialysis patients in NT increased 88% from 277 in 2004 to 521 in 2013.
- The percentage of people dialysing at home increased from 11% to 13% of the total population between 2004 and 2013.
- The total number of home dialysis patients rose from 30 in 2004 to 67 in 2013.
- During this period home haemodialysis patients increased from 4 to 34.

As at December 2013, there were 34 home haemodialysis patients in Northern Territory (ANZDATA). It can be calculated that the 34 patients who have chosen home haemodialysis instead of satellite dialysis currently **reduce health budget costs by nearly $550,052** annually in Northern Territory (based on a $16,178 cost difference in modalities explained below).

Using the annual costs of **$65,315 for satellite haemodialysis patients** and **$49,137 for home haemodialysis patients** (KHA 2010 national prices), the likely costs to the NT Health budget as a result of either existing home patients switching to satellite dialysis or potential new home patients choosing satellite dialysis because of the power costs associated with home dialysis can also be calculated.

This is a conservative calculation as the average national annual cost of **hospital haemodialysis is $79,072** and while some hospital haemodialysis supports acute patients, it also provides dialysis to patients who would be suitable for satellite or potentially home haemodialysis. According to the Central Australia Renal Study, the specific costs within the Northern Territory are even greater.
Hospital haemodialysis costs the territory $101,189, satellite dialysis costs $75,980 and home haemodialysis is the lowest cost at $54,017\(^2\).

Since 2004, an additional 225 people or 81% are now undertaking dialysis. The 2013 numbers show a total of 521 patients on dialysis with 454 of those on satellite or hospital dialysis. The Northern Territory has one of the lowest rates of home haemodialysis in the country at 6%. The national average is 9%, and New South Wales holds the highest rate, with 12%.

5. Discussion

Within other jurisdictions, home haemodialysis can provide the best outcomes for appropriate patients and is also the most cost effective. Kidney Health Australia understands that there are low rates of home haemodialysis patients in the Northern Territory. However, the reasons for low rates of home haemodialysis in the Northern Territory may be due to a higher proportion of Indigenous patients who face complex barriers to access, higher rates of infections or adverse health outcomes, or they may have a preference for in-centre dialysis or self-dialysis.

Where it is appropriate for a patient to take up home haemodialysis in the Northern Territory there are many considerations. These can include patient preparedness such as personal competence, availability of a carer and convenience; physical set up including access and costs for power and water and cultural factors including understanding, acceptance and spirituality around kidney illness. All these factors need to be weighed up against transport time and transport costs to available satellite or hospital centres, where utility costs and incidentals are all covered, food provided and professional medical staff are available.

If it is appropriate for a patient to undertake home haemodialysis, there are out of pocket expenses. A summary of the issues facing a person who is currently eligible for home dialysis, but is also considering satellite or hospital dialysis, is presented in the following Table.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Satellite / Hospital Dialysis</th>
<th>Home Haemodialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Set up costs</td>
<td>Nil</td>
<td>Includes chair, storage for consumables, plumbing and electrical alterations. May cost up to $3,000</td>
</tr>
<tr>
<td>Training requirements</td>
<td>None</td>
<td>Patient and carer training required, which can necessitate travel and accommodation for the duration of training</td>
</tr>
<tr>
<td>Running costs</td>
<td>Nil</td>
<td>Electricity up to about $1,000 per annum. Water up to about $250 per annum</td>
</tr>
<tr>
<td>Ongoing Transport costs</td>
<td>Variable cost and time. May require assistance with transport.</td>
<td>Nil</td>
</tr>
<tr>
<td>Convenience</td>
<td>Has to fit in with the satellite centre’s schedule. May require assistance with transport.</td>
<td>Can dialyse on days / times that suits the patient. May require carer assistance.</td>
</tr>
<tr>
<td>Medical outcome</td>
<td>Good</td>
<td>Better</td>
</tr>
</tbody>
</table>

The Northern Territory Renal Services Framework 2012-2017 outlines the future direction and priorities for the service and focuses on six priority areas. These six priorities are fundamental to the development of the dialysis home therapies program and of particular relevance is the priority to enable renal patients to have treatment closer to home. The Department of Health NT states:

> The goals for the Home Therapies program as outlined in the Renal Services Framework 2012-2017 is reflected in the adoption of a “Home Therapies First Policy” and responds to client related demand drivers such as loss of health independence, limited options of care and the burden of dislocation from their home community.³

The Northern Territory Implementation Plan 2014-2016 promoted strategic directions to assist with the development of service plans. Notably, the document mentions:

- Reducing health disparities amongst different population groups with regard to conditions and chronic disease (including Chronic Kidney Disease);
- Maximise the wellbeing of those living with chronic conditions;
- Improved access to chronic conditions services closer to home.

The Central Australia Renal Study also supports these plans, and in particular in discussing home dialysis options states:

> Protocols for dialysis treatment closer to home in the particular circumstances of the CA [Central Australia] region must be agreed and formalised – Safe and sustainable renal service provision in remote communities requires specification of a broad range of

well-documented environmental factors, including location, services, design, construction, water, electricity, drainage and management of bio-hazardous waste.\textsuperscript{4}

Despite each home haemodialysis patient reducing the cost to the NT Health budget by between $21,000 and $47,000 annually by their choice of modality, patients are currently bearing considerable out-of-pocket costs as a result of increased power costs compared to satellite or hospital patients.

This lack of uptake for home haemodialysis patients is also contrary to the stated aim in the Northern Territory Implementation Plan of promoting adequate health services closer to patient homes:

“Improve access to health services for all Territorians: many people have difficulty in accessing health services. Barriers include health literacy, language and distance...Promoting delivery of chronic conditions care closer to home is key”\textsuperscript{5}

Haemodialysis patients should be subsidised at an increased rate due to the significant out of pocket expenses incurred. The cost to subsidise such few patients would have a minimal financial impact to the Government, but would allow significant cost savings within the Northern Territory Health Budget.

6. Conclusions

Current subsidies for power usage for home dialysis patients are inadequate leaving a shortfall of some $868.90 per annum. This is a disincentive and may create unintended financial hardship for current home haemodialysis patients, resulting in a return to hospital-based or satellite renal dialysis.

Both the Northern Territory Implementation Plan 2014-2016 and the principles stated in the Northern Territory Renal Services Framework 2012-2017 support the use of home therapies.

There are greater savings to the Health system in the Northern Territory by enabling home haemodialysis, where appropriate. Those small number of home haemodialysis patients should not be financially disadvantaged by their choice of modality to dialyse at home rather than hospital and satellite dialysis services.

7. Recommendations

There are a range of concessions and subsidies which could be implemented in the Northern Territory to assist.

These include:


\textsuperscript{5}http://digitallibrary.health.nt.gov.au/prodjspui/bitstream/10137/608/1/NT%20Implementation%20Plan%202014-2016_FINAL.pdf
• Annual payment to patients for home haemodialysis (CPI indexed). For example, in Victoria patients are eligible for $1,990 per year in direct payments
• Discount on Annual Energy Bills – For example in Victoria, there is a 17.5% discount on energy bills for concession card holders.\(^6\)
• Rebates – Discounts offered on life saving equipment in Victoria is equal to the cost of 1,880 kilowatts per year. Victoria also offers discounts on usage such as water, and provides a special dispensation rebate on water bills equal to the cost of 168 kilolitres of water per year.

We strongly advocate exploring options to assist with alleviating the financial burdens on home HD patients in NT.

**Reference**

Kidney Health Australia, 2010, *The Economic Impact of End-Stage Kidney Disease in Australia: Projections to 2020*, p. 27.

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\(^6\) The Northern Territory Pensioner and Carer Concession Scheme provides general concessions on some utility costs for holders of various concession cards. This rate can be variable and determined by Centrelink (Department of Human Services)
**Analysis Explanation:**

Calculation of the potential financial impact that low rates in home haemodialysis has had over the last two years on the health system using average national data

<table>
<thead>
<tr>
<th>Patient modality</th>
<th>Hospital Haemodialysis</th>
<th>Satellite Haemodialysis</th>
<th>Home PD</th>
<th>Home Haemodialysis</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ave Annual Cost of treatment</td>
<td>$79,072</td>
<td>$65,315</td>
<td>$53,112</td>
<td>$49,137</td>
<td></td>
</tr>
<tr>
<td><strong>2010 Actual Patients</strong></td>
<td>38</td>
<td>335</td>
<td>39</td>
<td>27</td>
<td>439</td>
</tr>
<tr>
<td>Cost of Actual 2010 Treatment</td>
<td>$3,004,736</td>
<td>$21,880,525</td>
<td>$2,071,368</td>
<td>$1,326,699</td>
<td>$28,283,328</td>
</tr>
<tr>
<td><strong>2013 Actual Patients</strong></td>
<td>33</td>
<td>421</td>
<td>32</td>
<td>34</td>
<td>520</td>
</tr>
<tr>
<td>Cost of Actual 2013 Treatment</td>
<td>$2,609,376</td>
<td>$27,497,615</td>
<td>$1,699,584</td>
<td>$1,670,658</td>
<td>$33,477,233</td>
</tr>
</tbody>
</table>

(An 18% increase from 2010)

**Calculation of potential 2016 patient numbers (at 18% increase proportionately)**

| | 39 | 497 | 38 | 40 | 613 |
|---|---|---|---|---|
| Cost of treatment calculation | $3,083,808 | $32,461,555 | $2,018,256 | $1,965,480 | $39,529,099 |

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Kidney Health Australia, 2010, *The Economic Impact of End-Stage Kidney Disease in Australia: Projections to 2020*,

Appendix A - Page 1
Appendix B:

Home Dialysis Power Usage Analysis for Northern Territory
1. Purpose

This analysis seeks to quantify current electricity usage by home haemodialysis patients at the present time with present rates. Even though a conservative approach has been applied to this new analysis (rates of electricity have been selected based only on a two person household) it still demonstrates considerable out of pocket costs.

2. Input Data for Power Costs

The Northern Territory has one main electricity provider, Jacana Energy. Rates were taken directly from Jacana Energy’s website.

3. Current Home Dialysis Practice

Although home dialysis practices vary somewhat the current recommended practice is for 5 hours dialysis every second day. Allowing for 1 hour for setup and cleanup that totals 1,095 running hours per annum (6 x 365/2).

Due to the improved health outcomes, a number of dialysis patients are opting for nocturnal dialysis every second day which entails minimum 8 hours dialysis. Again, allowing 1 hour for setup and cleanup that totals 1642 running hours per annum (9 x 365/2).

4. Dialysis Machine Power Usage

Dialysis power usage averages approximately 2,000 watts/hour for the dialysis machine and 400 watts/hour for the reverse osmosis (RO) unit (data supplied by Sydney Dialysis Centre), totalling 2400 watts/hour.

5. Dialysis Machine Power Costs

Table 1 illustrates usage calculated for a power meters in Northern Territory. It clearly demonstrates that there is still considerable burden to patients choosing to dialyse at home and that all the arguments of the original analysis are sustained.


**Table 1 – Cost for Dialysis in Northern Territory**

<table>
<thead>
<tr>
<th>Jacana Energy</th>
<th>6 hour dialysis</th>
<th>9 hour nocturnal dialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hours per annum</td>
<td>1,095</td>
<td>1,642</td>
</tr>
<tr>
<td>Power cost/kWh</td>
<td>0.2560</td>
<td>0.2560</td>
</tr>
<tr>
<td>Power usage kW/hr</td>
<td>2.40</td>
<td>2.40</td>
</tr>
<tr>
<td>Annual power usage kWh</td>
<td>2,628</td>
<td>3,941</td>
</tr>
<tr>
<td>Annual power cost</td>
<td>$672.77</td>
<td>$1008.90</td>
</tr>
<tr>
<td>Annual dialysis rebate</td>
<td>$140</td>
<td>$140</td>
</tr>
<tr>
<td>Net annual cost to user</td>
<td>$532.77</td>
<td>$868.90</td>
</tr>
</tbody>
</table>

6. **Conclusion**

From the data presented above, the impact of increasing electricity prices continues to inflict a considerable burden on patients who have chosen to undertake home haemodialysis. The cost burden exceeds $800 per annum for those patients undertaking nocturnal dialysis using a conventional power meter in remote and very remote areas, and it should be considered that that scenario has an assumption that town water is available and that additional electricity isn’t being used towards running water pumps on tanks.

Similarly, throughout this analysis, consideration has only been for the delivery of the dialysis, not for the typical scenario that a dialysis patient will likely also be consuming additional power through secondary requirements such as personal air conditioning and the use of television during the dialysis time.
Recommendation:

That each State Government introduce a much needed respite program for dialysis consumers, similar to the “Enable” scheme currently operating in NSW and the ACT.

Issue:

Chronic Kidney Disease (CKD) is common, with one in ten Australians over 18 showing evidence of the disease. Once diagnosed, lifestyles for consumers are drastically changed. In order to survive with End Stage Kidney Disease (ESKD), a patient has only two options: ongoing dialysis treatment or transplantation. There is no relief for consumers and their families from the constant stress of the treatment regimen.

Dialysis restricts the ability to travel because the nature of dialysis treatment is that it is undertaken at least three days a week, for at least four hour sessions per treatment. One objective of dialysis is to facilitate for a patient as normal a life as possible. This lifestyle should include the ability to travel for a range of reasons. Providing the ability for travel respite for dialysis consumers would come at a negligible cost to governments, but provide significant improvement to quality of life for patients and their families.

The impact of dialysis treatment – and the opportunity to “take a break”

The inability for travel rules out many important life events – such as a wedding, funeral, or birth of a new child in the family. In a recent national dialysis patient survey, Kidney Health Australia’s Consumer Perspectives on Dialysis, 70% of dialysis patients found it difficult or impossible to take a holiday.

Without a consumer being able to secure dialysis at their destination, travel simply isn’t an option. Most states and territories in Australia have “Renal Plans” set by each state Department of Health which identify the restrictions and limitations dialysis has on those living with and caring for people with renal disease, including the difficulty in taking holiday or securing respite, and the need to provide some level of assistance to achieving this goal.

Furthermore, Kidney Health Australia’s National Consumer Council, which represents consumers from each jurisdiction in Australia, has continually reported that one of the worst effects of dialysis from a consumer perspective is the inability to have any respite or travel interstate.
Marianne’s situation highlights the inflexible nature of dialysis and the implications of life without the ability to travel interstate. If a system was in place that would allow interstate travel from Queensland and Victoria, it may be entirely plausible that for two weeks per annum, Marianne’s father could coordinate respite for his wife and simultaneously visit his family in Queensland, all while maintaining his dialysis routine.

**Providing holiday dialysis options in Australia**

Currently, there is a program present in Australia that addresses the issue of holidays for those on dialysis, in both a low cost and efficient manner. New South Wales (NSW) and the Australian Capital Territory (ACT) have established programs for patients in their jurisdictions to allow a method for vacation travel.

In NSW, Enable NSW runs the program called “Away From Home Haemodialysis (AFHH) Program”. Eligible patients may access up to three sessions per year at one of the participating private renal units located away from their usual place of residence. The NSW Government has negotiated this system with various private clinics across NSW, Victoria, Queensland, South Australia, Western Australia, the Northern Territory and the ACT. The program is available to any NSW resident undergoing either haemodialysis at home or in a centre-based dialysis unit. This means the patient choice in modality does not further preclude them from the ability to travel interstate.

The ACT has also introduced a travel voucher scheme, run in the same manner as Enable NSW. Three “vouchers” are provided each year for separate visits to interstate clinics run by private dialysis clinics.
Kidney Health Australia’s ongoing work to help kidney consumers “take a break”

Kidney Health Australia understands that for patients and their families, there are unique challenges that come with living with, or supporting someone with ESKD. To this end, KHA has a number of initiatives for consumers on a national level, and work to provide the ability for consumers to have much needed reprieve that would work very well in conjunction with an “Enable” scheme.

In 2014, Kidney Health Australia and Monash Health Victoria launched the first “Big Red Kidney Bus” (BRKB) in Australia. This project has been highly successful in providing consumers with holidays in Victoria and it has also led to a decision for Kidney Health Australia to support similar project in other states. The BRKB is staffed by two renal nurses, and contains three chairs, staying in a single holiday destination in Victoria for six weeks prior to relocating.

The overall vision of Kidney Health Australia is a fleet of “Big Red Buses” to extend holiday dialysis to places in Australia where renal units don’t exist, and a much needed “Enable” system for they do exist. If both these systems were operating in Australia, they would be able to work together to improve the quality of life for dialysis consumers.

Cost equalisation to Government

It should be noted that from a Government perspective, providing an “Enable” system works out to be at little to no cost to the host state health system. This is due to the service agreements that are pre-arranged with specific private dialysis units in other states. Under the NSW Enable scheme, the interstate dialysis unit places a charge directly back to NSW. This would be no different if the consumer chose to remain in NSW and dialyse in centre, where the cost would be as per normal.

Recommendation

Kidney Health Australia recommends that the programs which are run by both NSW and ACT be replicated in other jurisdictions around Australia. There is currently minimal opportunity to obtain respite for patients or their families on a dialysis regimen outside of NSW and the ACT, and this has a significant impact on quality of life.

There is a great opportunity for the remaining states to replicate a scheme which, by government standards, is small in cost to run. Abrupt changes in lifestyle and loss of freedom to travel are primary concerns of patients with CKD. Providing a travel voucher system would serve to counter these deterrents and focus on the positive aspects of life available to patients with kidney disease and their families.

**ANZDATA:**
**Dialysis Rates in Northern Territory (2014)**

Total: 557  
Hospital Haemodialysis: 489  
Home Haemodialysis: 41  
Peritoneal Dialysis: 27