Kidney Health Australia

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Dear Ms Haddad,

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 in your community consultation process. 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

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relevant and targeted investments that could be made in the forthcoming state budget.

Yours sincerely

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KIDNEY HEALTH AUSTRALIA

The Impact of Increased Power Costs on Home Haemodialysis Tasmania

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 Tasmania.

2. Background

Increases in the cost of electricity continue to contribute to the situation where home haemodialysis patients face significant out-of-pocket costs of up to approximately $859 per annum (refer attached analysis – Appendix B). Figure 1 illustrates the number of Tasmanian dialysis patients by mode of dialysis between 2004 and 2013 (Source – ANZDATA).

Points worth noting from Figures 1 includes:

- The total number of dialysis patients in Tasmania increased 52% from 147 in 2004 to **216** in 2013.
- The total number of home dialysis (haemodialysis and peritoneal dialysis) patients rose from 34 in 2004 to 57 in 2013.
- The percentage of people dialysing at home increased from 23% to 26% of the total Tasmanian dialysis population between 2004 and 2013.
- During this period home haemodialysis patients increased from 7 to 17, an increase that is only 14% of the overall patient number that commenced dialysis.

Tasmania has a low rate of home haemodialysis and shows a very marginal increase not synonymous with the growth of total dialysis patients during the same timeframe. An important step to improve the uptake of patients choosing to dialyse at home would be to alleviate some of the significant out of pocket electricity costs they are currently facing.

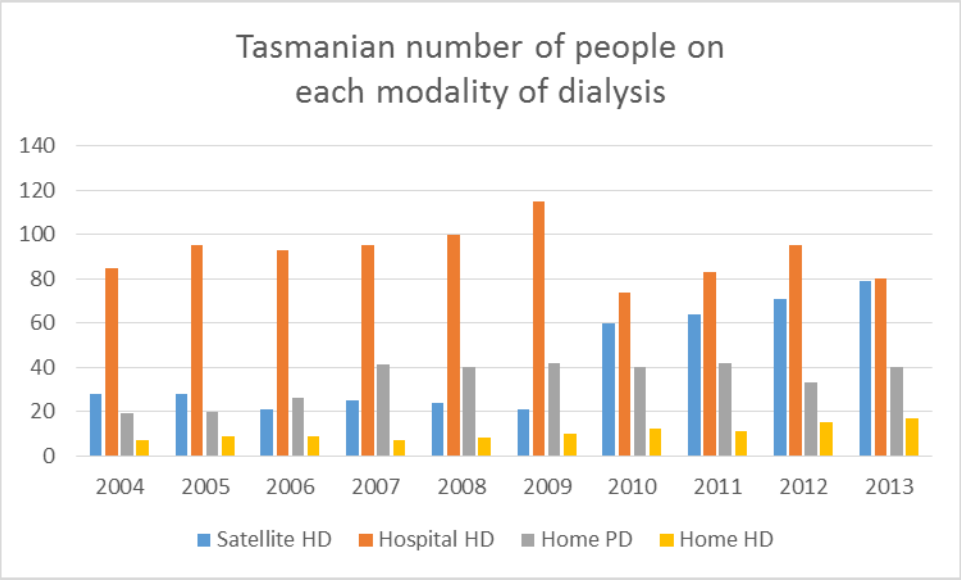

Figure 1 – Number of Tasmanian patients undergoing dialysis by mode

As at December 2013, there were 17 home haemodialysis patients in Tasmania (ANZDATA). It can be calculated that the 17 patients who have chosen home haemodialysis instead of satellite dialysis currently reduce health budget costs by nearly $275,026 annually in Tasmania (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 prices), the likely costs to the Tasmanian 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.

Since 2004, an additional 69 people or 47% are now undertaking dialysis. The 2013 numbers show a total of 216 patients on dialysis with 159 of those on satellite or hospital dialysis. Tasmania has a low rate of low cost home based dialysis. Tasmania is currently dependent upon the more expensive modalities of satellite and in-centre haemodialysis. Changing this mix of modalities, and and increasing home-based treatments would deliver savings estimated at $825,078 per annum based on a 50% split of home based to in-centre based dialysis (an additional 51 people moving to home based dialysis).

The impact of increasing electricity prices continues to inflict a considerable burden on patients who have chosen to undertake home haemodialysis. The cost burden can be approximately $500-$800 per annum depending on dialysis modality[1].

[1] Refer to Appendix B for further analysis

3. Discussion

It is well recognised that home haemodialysis provides the best outcomes for appropriate patients and is also the most cost effective.

For a patient to take up home haemodialysis there are many considerations, including personal competence, availability of a carer, convenience, set up costs and running cost for power and water. 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.

The Tasmanian State Renal Plan 2010-2020 identified that the increase in home based home dialysis could provide a cost saving:

> The current mix of treatment modalities for dialysis patients in Tasmania is very dependent upon the more expensive modalities of satellite and in-centre haemodialysis, with lower than national rates of use in the less expensive home-based therapies. Changing this mix of modalities and increasing home-based treatments would deliver savings estimated at $16.2m and would likely be associated with improvements in quality of life.[2]

In 2011 Kidney Health Australia published its *"Report on Consumer Perspectives on Dialysis – First National Census."* Analysis of the data from Tasmania about the willingness of those not currently dialysing at home to change to home dialysis was surveyed and the results are shown in Figure 2. There are a considerable number of respondents who indicated their willingness to consider home dialysis if expenses were reimbursed.

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[2] http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0010/57178/State_Plan_Renal_Services_January_2010.pdf

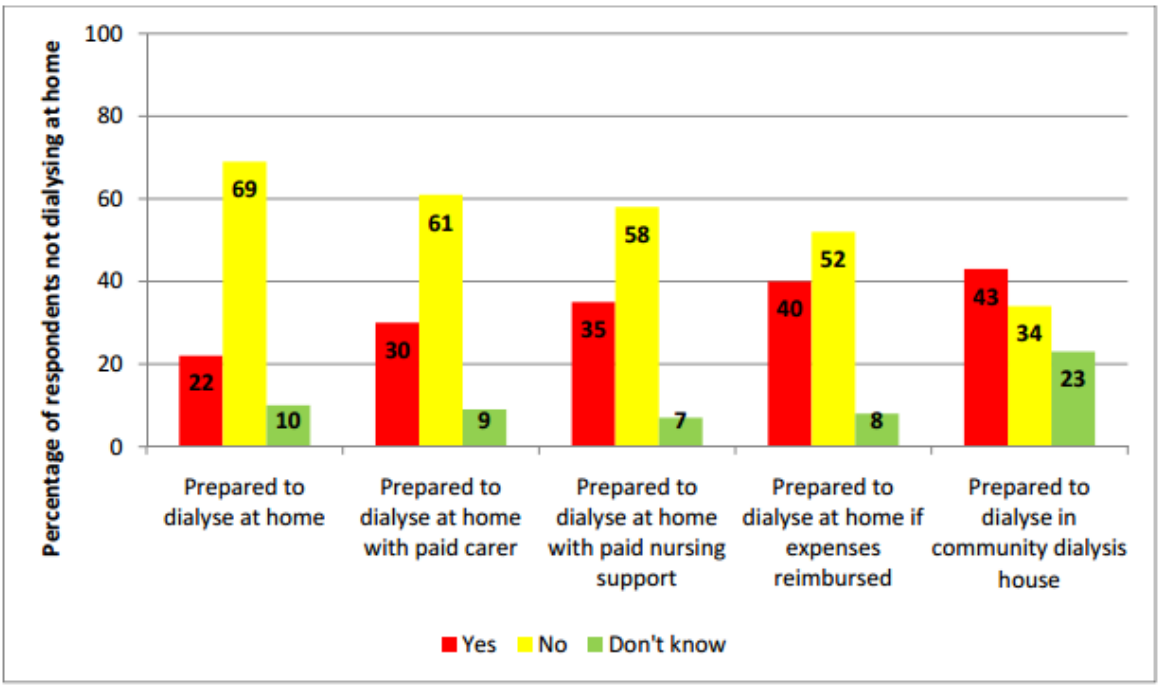

Figure 2 – Willingness of Tasmanian patients to dialyse at home.

The Tasmanian Renal Health Plan (*State Plan for Renal Services 2010-2020)* had clear recommendations and objectives listed in order to oversee a renal service in Tasmania that will deliver solutions for future challenges. Notably, the document mentions:

> Ensure patients undertaking self-care therapies are not 'out of pocket' as a result of minor infrastructure changes to homes or increased recurrent costs related to essential services. Renal Services should undertake the necessary liaison with councils, power and water authorities to facilitate concessions and provide reimbursements where necessary.[3]

Despite each home haemodialysis patient reducing the cost to the Tasmanian Health budget $16,000 up to $30,000 annually by their choice of modality, they are currently bearing considerable out-of-pocket costs as a result of increased power costs compared to satellite or hospital patients. This is an inequitable situation and is certainly not a smart choice regarding costs and benefits. It is also clearly creating an increasing demand for satellite dialysis infrastructure.

As a corollary to the argument that the cost of providing dialysis would rise as a result of patients rejecting the option of home haemodialysis because of the costs involved, if more patients were to choose home haemodialysis as a result of removal of financial barriers, the dialysis associated costs would fall.

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3 http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0010/57178/State_Plan_Renal_Services_January_2010.pdf

4. Comparison between satellite and home haemodialysis

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.

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

It is obvious that, if financial constraints are paramount, then the choice of modality is weighted heavily against home haemodialysis in the current climate.

5. Conclusions

Current subsidies for power usage for home dialysis patients are inadequate and inequitable and are leading to a growing number of current home dialysis patients being unable to sustain home haemodialysis and a reduction in the number of patients electing this modality.

This is contrary to the aims of the Tasmanian Renal Health Plan (*State Plan for Renal Services 2010-2020).*

Unaddressed, this situation is clearly leading to increased costs in the Health budget and a greater demand for hospital and satellite dialysis services.

6. Recommendations

For several years now, Victoria has had in place a successful arrangement which offers:

- A $1,990 per patient per annum payment for home haemodialysis (CPI indexed).
- A $755 per patient per annum payment for home peritoneal dialysis (CPI indexed).
- A 17.5% discount on annual energy bills for concession card holders.
- Concession card holders may also be eligible to receive a rebate of up to $277 per year.

- Life Support machine concession – the discount is equal to the cost of 1,880 kilowatts per year.

We would strongly advocate that the Victorian model be considered, or at very minimum, the rates under the current arrangement be commensurate with the Victorian rates as listed above. Kidney Health Australia willingly offers to assist collaboratively in providing further analysis to demonstrate the potential savings such an incentivising model would ultimately deliver.

Reference

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

Analysis Explanation:

Calculation of the potential financial impact that low rates in home haemodialysis has had over the last three years on the health system

Patient modality	**Hospital Haemodialysis**	**Satellite Haemodialysis**	**Home PD**	**Home Haemodialysis**	**Total**
Ave Annual Cost of treatment[4]	$79,072	$65,315	$53,112	$49,137	
2010 Actual Patients	74	60	46	12	192
Cost of Actual 2010 Treatment	$5,851,328	$3,918,900	$2,390,040	$589,644	$12,749,912
2013 Actual Patients	80	79	40	17	216 (a 12.5% increase on 2010)
Cost of Actual 2013 Treatment	$6,325,760	$5,159,885	$2,124,480	$835,329	$14,445,454
Calculation of potential 2016 patient numbers (based on 12.5% increase proportionately)	90	89	45	19	243
Cost of treatment calculation	$7,116,480	$5,813,035	$2,390,040	$933,603	$16,253,158
Anticipated increase from 2013 actual to calculated 2016 dialysis delivery costs if modalities rates stay the same **It is suggested that action on the impact of increasing electricity costs and the associated out of pocket expenses for home patients could reduce cost barriers for modality choice and positively impact projected financial outcome.**					**$1,807,704**

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

Appendix B:

Home Dialysis Power Usage Analysis for Tasmania

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 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

For the purpose of this exercise, residential power costs on the following distribution grid has been used:

- Aurora Energy

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 Tasmania. 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 Tasmania

	Aurora Energy	
	6 hour dialysis	**9 hour nocturnal dialysis**
Hours per annum	1,095	1,642
Power cost/kWh	0.24717	0.24717
Power usage kW/hr	2.40	2.40
Annual power usage kWh	2,628	3,941
Annual power cost	$649.56	$974.09
Annual dialysis rebate	$114.23	$114.23
Net annual cost to user	**$535.33**	**$859.86**

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 regional and rural 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 heating or cooling and the use of television during the dialysis time.

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"Enable" Visa System

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.

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Case Study

Marianne lives in Caboolture, Queensland, approximately ninety minutes north of Brisbane. Her father is eighty years old and based in Melbourne. He has been on dialysis for the last seventeen years. Although her father has end stage kidney disease, he is also the primary carer for his wife who suffers from severe dementia. Due to the inability for her father to travel and secure dialysis appointments in Queensland, he has missed out on not only family holidays, but the birth of his grandchildren, weddings of his family members, and no time away as the primary carer of his wife. Marianne's father also needs dialysis at regular intervals which due to doctor advice, cannot be changed.

Marianne is under extreme stress as her father is simply unable to secure the ability for time with his extended family, and for respite for himself. Earlier this year, when contemplating a trip for late 2015, the only dialysis clinic in Queensland that was willing to accommodate him was located in Nambour which is over an hour away from Marianne's home. Further, the clinic in Nambour was unable to medically accommodate his dialysis routine as required by his Nephrologist due to a lack of dialysis chairs available.

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.

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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 Tasmania (2014)

Total: 227
Hospital Haemodialysis: 163
Home Haemodialysis: 25
Peritoneal Dialysis: 39