

22 February 2016

Hon. Tom Koutsantonis MP
Treasurer
Department of Treasury & Finance
200 Victoria Square
Adelaide, SA 5000

Dear Treasurer,

Kidney Health Australia
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The Australian Kidney Foundation
Trading as Kidney Health Australia
ABN 37 008 464 426 | Charity No. CH 0614

Patron-in-Chief
His Excellency General
The Honourable Sir Peter Cosgrove AK MC
(Retired)

Patrons
Lady Margaret Brabham
Mr Normie Rowe AM

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

"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.

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.

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 South Australia (2014)

Total: 742
Hospital Haemodialysis: 581
Home Haemodialysis: 33
Peritoneal Dialysis: 128



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The Impact of Increased Power Costs on Home Haemodialysis South Australia

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 South Australia (SA).

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 \$1,000 per annum (refer attached analysis – Appendix B). Figure 1 illustrates the number (expressed as a %) of South Australian dialysis patients by mode of dialysis between 2004 and 2012 (Source – ANZDATA).

Points worth noting from Figures 1 includes:

- The total number of dialysis patients in SA increased 5.5% from 695 in 2004 to **733** in 2012.
- The percentage of people dialysing at home increased from 21% to 22% of the total population between 2004 and 2012.
- The total number of home dialysis (haemodialysis and peritoneal dialysis) patients rose from 111 in 2004 to 163 in 2012.
- During this period home haemodialysis patients increased from 14 to 22.

South Australia has a low rate of home haemodialysis (the lowest in Australia) 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. South Australia has experienced one of the highest rises of electricity costs in the nation through the same period which has accentuated the additional cost burden on home dialysis patients¹.

¹ Australian Bureau of Statistics, Report 4670.0 - Household Energy Consumption Survey, Australia, <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4670.02012?OpenDocument>

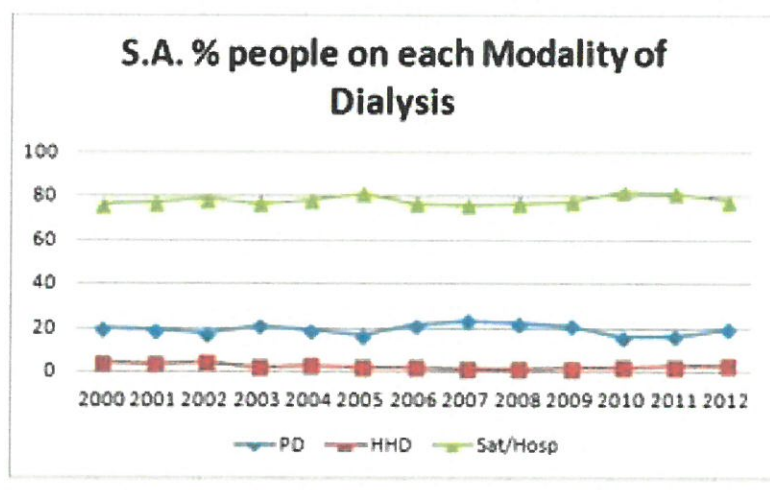


Figure 1 – Percentage of SA patients undergoing dialysis by mode

As at December 2012, there were 22 home haemodialysis patients in South Australia (ANZDATA). It can be calculated that the 22 patients who have chosen home haemodialysis instead of satellite dialysis currently reduce health budget costs by nearly \$355,916 annually in South Australia (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 SA 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 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.

Since 2004, an additional 38 people or 5.5 % are now undertaking dialysis. The 2012 numbers show a total of 733 patients on dialysis with 570 of those on satellite or hospital dialysis. South Australia has the lowest rate of home haemodialysis in the country at 3% of total dialysis patients compared to the national figure of 9%. The highest percentage of all states and territories is in NSW, with 12%. If the South Australian government had home dialysis rates consistent with the national rate, it would save **\$1,317,140** per annum. If the NSW rate was achieved, the savings could be calculated at **\$1,975,710** per annum.

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 SA Clinical Network identified KPIs for home dialysis stating:

Apart from transplantation, home based dialysis is the recommended choice by nephrologists for patients with End Stage Kidney Failure and it is preferred by funding bodies as the most cost effective form of dialysis. Home dialysis treatments can provide significant social and lifestyle benefits. Home haemodialysis enables patients to have longer and more frequent dialysis treatments. Emerging observation data indicates this gives significant survival advantage.²³

In 2011 Kidney Health Australia published its *“Report on Consumer Perspectives on Dialysis – First National Census.”* Analysis of the data from South Australia about the willingness of those not currently dialysing at home to change to home dialysis was surveyed and the results are shown in Figure 4. There are a considerable number of respondents who indicated their willingness to consider home dialysis if expenses were reimbursed.

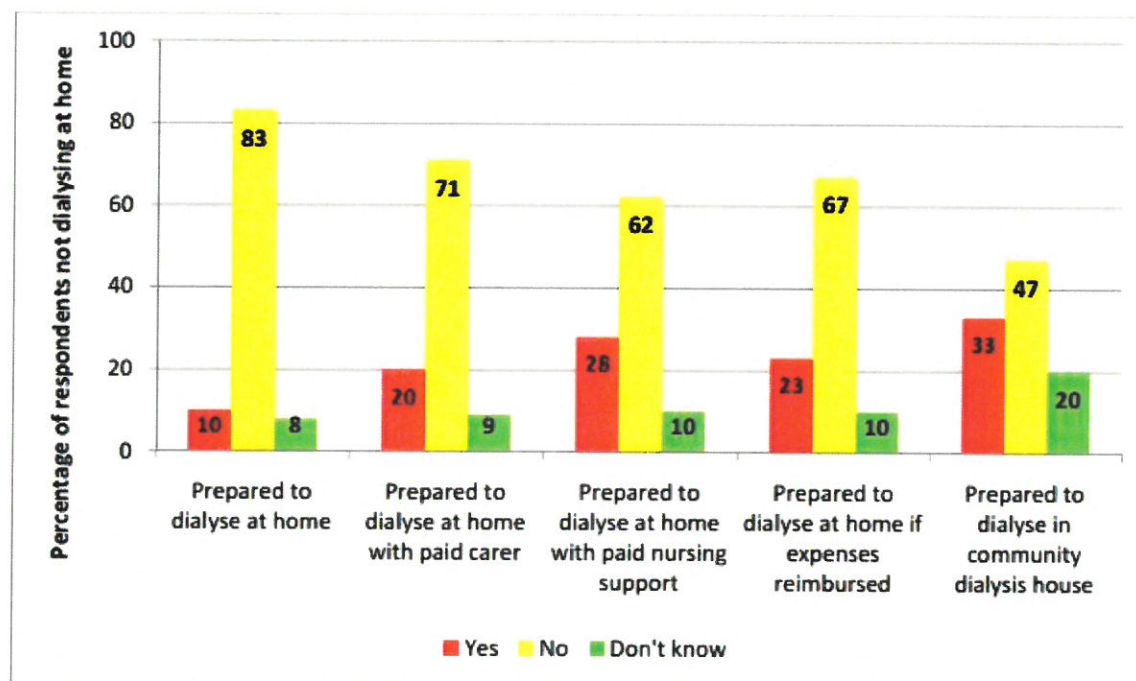


Figure 2 – Willingness of SA patients to dialyse at home.

³ <http://www.sahealth.sa.gov.au/wps/wcm/connect/9010bd80453022288e54de005ba75f87/SA-Renal-KPI%27s-Feb-2014-final.pdf?MOD=AJPERES&CACHEID=9010bd80453022288e54de005ba75f87>

The SA State Health Plan (*Our Health: South Australia's Strategic Plan*) promoted strategic directions to assist with the development of service plans. Notably, the document mentions:

- Chronic disease reduces our quality of life and makes up more than 70% of diseases;
- Increase, by five percentage points, the proportion of people living with a chronic disease whose self-assessed health status is good or better.

Despite each home haemodialysis patient reducing the cost to the SA 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.

This lack of equity for home haemodialysis patients is also contrary to the stated aim in the SA State Health Plan of promoting equity of access to health services:

“SA Health strives to protect and enhance the health and wellbeing of people by working cooperatively with other agencies and the community to develop healthy environments and support behaviours that protect and promote good health, reduce health risk factors, and enhance health outcomes and **reduce health inequalities**”⁴

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.

It should be noted that there has been an increase in the number of people on home haemodialysis in South Australia. Although not yet published, as of 1 October 2014, this number has risen to 33. This is a 50% increase on the 2012 numbers. While this increase is encouraging it does not detract from the problems identified in this paper. With suitable compensation for the increased cost of power it is believed that the number of people on home haemodialysis would further increase toward the national norm.

4

http://www.sahealth.sa.gov.au/wps/wcm/connect/a1b9198042602f06b8debeb44d317729/Strategic_Plan_Revised2_2013.pdf?MOD=AJPERES&CACHEID=a1b9198042602f06b8debeb44d317729

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 SA Clinical Network Strategy and the principles stated in the SA State Health Plan.

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.
- Water – special dispensation rebate on water bills equal to the cost of 168 kiloliters of water 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 two years on the health system

| <i>Patient modality</i> | Hospital Haemodialysis | Satellite Haemodialysis | Home PD | Home Haemodialysis | Total |
|--|---------------------------|----------------------------|-------------|-----------------------|---------------------|
| Ave Annual Cost of treatment ⁵ | \$79,072 | \$65,315 | \$53,112 | \$49,137 | |
| 2010 Actual Patients | 87 | 465 | 95 | 15 | 674 |
| Cost of Actual 2010 Treatment | \$6,879,264 | \$30,371,475 | \$5,045,640 | \$737,055 | \$43,033,434 |
| 2012 Actual Patients | 95 | 475 | 141 | 22 | 733 (8% on 2010) |
| Cost of Actual 2012 Treatment | \$7,522,840 | \$31,024,625 | \$7,488,792 | \$1,081,014 | \$47,117,271 |
| | | | | | |
| Calculation of potential 2014 patient numbers (based on 8% increase proportionately) | 103 | 513 | 152 | 24 | 792 |
| Cost of treatment calculation | \$8,144,416 | \$33,506,595 | \$8,073,024 | \$1,179,288 | \$50,903,323 |
| Difference between 2012 Actual and potential cost to the health system if modalities rates stay the same | | | | | \$3,786,052 |
| It is suggested that action on the impact of increasing electricity costs for home patients would have reduced this imbalance and resulting financial impact. | | | | | |

⁵ 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 South Australia

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

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

- AGL Australia
- Energy Australia
- Origin 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 ($6 \times 365/2$).

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 ($9 \times 365/2$).

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 South Australia. 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 South Australia

| | AGL | | Energy Australia | | Origin | |
|-------------------------|-----------------|---------------------------|------------------|---------------------------|-----------------|---------------------------|
| | 6 hour dialysis | 9 hour nocturnal dialysis | 6 hour dialysis | 9 hour nocturnal dialysis | 6 hour dialysis | 9 hour nocturnal dialysis |
| Hours per annum | 1,095 | 1,642 | 1,095 | 1,642 | 1,095 | 1,642 |
| Power cost/kWh | 0.33528 | 0.33528 | 0.39380 | 0.39380 | 0.37180 | 0.37180 |
| Power usage kW/hr | 2.40 | 2.40 | 2.40 | 2.40 | 2.40 | 2.40 |
| Annual power usage kWh | 2,628 | 3,941 | 2,628 | 3,941 | 2,628 | 3,941 |
| Annual power cost | \$881.12 | \$1321.33 | \$1034.90 | \$1551.97 | \$977.09 | \$1465.26 |
| Annual dialysis rebate | \$165 | \$165 | \$165 | \$165 | \$165 | \$165 |
| Net annual cost to user | \$716.12 | \$1156.33 | \$869.90 | \$1386.97 | \$812.09 | \$1300.26 |

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 \$1,000 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.