

22 February 2016

Hon. Mike Nahan MP
Treasurer
Department of Treasury & Finance
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Patron-in-Chief
His Excellency General
The Honourable Sir Peter Cosgrove AK MC
(Retired)

Patrons
Lady Margaret Brabham
Mr Normie Rowe AM

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 initiative proposed here will help ease the burden of kidney disease for both patients and carers. Having the ability to travel interstate when the need arises, is an issue our consumer committees have told us would go a long way in improving their quality of life.

Therefore, we have attached a policy paper for your consideration. It 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 this initiative, the cost to government is small, especially in comparison to the overall size of the health budget. This scheme would go a long way in removing barriers and improving their quality of life.

The intent behind the policy proposal we have attached is in line with the direction and principles supported in the recent findings and final report from the Legislative Council *Standing Committee on Public Administration's* Inquiry into the Patient Assisted Travel Scheme (PATS). The recommendations in the report included much needed subsidy increases for accommodation, fuel and travel for

those on dialysis in rural and regional areas. As such, we have also included our original submission to the Legislative Council Committee on the PATS scheme.

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

Yours sincerely

A handwritten signature in blue ink that reads 'Anne Wilson'.

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 Western Australia (2014)

Total: 1219
Hospital Haemodialysis: 936
Home Haemodialysis: 63
Peritoneal Dialysis: 220