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**KIDNEY
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Kidney Health Australia

Submission into interim report: A New System for Better Employment and Social Outcomes

7 August 2014

Kidney Health Australia welcomes the opportunity to provide input into the interim review report 'A New System for Better Employment and Social Outcomes' released by the Government on 29 June 2014. Kidney Health Australia would welcome the opportunity to expand upon this in person, as we feel strongly there is now an opportunity to address the inequitable approach to supporting those providing episodic, but critical care, for those on dialysis and that doing so can improve social and productive outcomes.

The State of Kidney Disease in Australia

It is estimated that approximately 1.7 million Australians over the age of 18 years have at least one clinical sign of existing CKD¹. CKD may further deteriorate into end-stage kidney disease (ESKD), when renal replacement therapy (RRT) - dialysis or transplantation - is required to stay alive.

Without kidney function death will occur in a matter of days. A total of 20,766 people were receiving renal replacement therapy – dialysis or kidney transplantation – at the end of 2012². This represents a 6.6% increase from 2011. Currently, 1,144 people are waiting for a kidney transplant in Australia³. The most recent data that is available from the Australia and New Zealand Dialysis Transplant (ANZDATA) Registry shows that 2,534 people started kidney replacement therapy (dialysis or transplantation) in 2012⁴.

The cost of treating ESKD is equally daunting. Economic modelling commissioned by Kidney Health Australia conservatively estimates that the cumulative cost of treating all current and new cases of ESKD from 2009 to 2020 Australia wide to be between \$11.3 billion and \$12.3 billion⁵. It can cost up to \$80,000 (2009 prices) per annum for one person to be on dialysis 'in-centre'. It can cost in excess of that in rural and remote areas. Kidney disease contributes to approximately 15% of all hospitalisations in Australia⁶.

¹ Australian Bureau of Statistics. Australian Health Survey: Biomedical Results for Chronic Diseases, 2011-12. ABS, Canberra; 2013.

² ANZDATA. 2013 Annual Report – 36th Edition; 2014. .

³ www.anzdata.org.au/anzod/v1/waitinglist2014.html

⁴ ANZDATA, 2014, op.cit.

⁵ Cass A, Chadban S, Gallagher M et al. The economic impact of end-stage kidney disease in Australia: Projections to 2020. Kidney Health Australia, Melbourne, Australia; 2010.

⁶ Australian Institute of Health and Welfare. *Australian hospital statistics 2009-10*. Canberra: Australian Institute of Health and Welfare; 2011.

The Australian Institute of Health and Welfare estimates that the number of people on dialysis is expected to increase by 80 percent by 2020 – rising from 11 to 19 per 100,000 of the Australian population⁷. The burden of CKD is distributed unequally and unfairly, as evidenced by the high rates of the condition in the lower socio-economic groups and in the Aboriginal and Torres Strait Islander community⁸.

Kidney Health Australia advocates on matters relating to the welfare of kidney stakeholders and the delivery of services to people affected by CKD in all its stages. Furthermore, Kidney Health Australia has close ties with consumers, the medical community, renal units around the nation and is a member of the Australian Chronic Disease Prevention Alliance (ACDPA) and the National Vascular Disease Prevention Alliance (NVDPA). Kidney Health Australia is committed to achieving its mission through engaging with renal sector professionals and consumer stakeholders in all initiatives and linking with other key chronic illness programs in an integrated way. Kidney Health Australia's work is carried out in consultation with the nephrological community and with significant input from our national network of consumers.

In its 46-year history, Kidney Health Australia has built a substantial evidence base to support its activities, and strong support from the community to continue to initiate efforts to reduce the incidence and impact of CKD. This submission represents areas where we believe current out of pocket costs are negatively impacting improved treatment of those with kidney disease, as well as the more efficient use of our limited health dollars.

The Role of Carers in Kidney Disease

With dialysis costing up to \$79,072 for hospital haemodialysis, \$65,315 for satellite, home haemodialysis \$49,137 and peritoneal dialysis \$53,112 (all 2009 prices), it is clearly an expensive treatment.

Living with kidney disease is an ongoing struggle. Dialysis, at a minimum, takes four to five hours at a time, three times a week. It requires either travelling to a satellite centre or hospital frequently, or undertaking dialysis at home. Those who chose not to dialyse at home, or are unable to for health reasons, often rely on carers to provide transport, noting that current arrangements through government or community organisations do not adequately provide for this.

For home dialysis, it often also requires the dedicated support of a carer, to set up, monitor and stabilise the dialysis machine if alarms should be triggered. This caring role can stem from 15 hours a week to in excess of 35 hours a week to assist with machine set up and cleaning, inserting needles, preparing meals, managing blood pressure and troubleshooting any issues.

Carers for home dialysis patients also require a significant investment of up to 6-8 weeks to participate in home dialysis training. Mobility and independence is dramatically reduced while undergoing dialysis. Transport to and from medical appointments, plus attendance at appointments, is often an added responsibility, as is the need to often limit work and recreational activities in favour of fulfilling their role as Carer. Carers play a particularly pivotal role in supporting home dialysis patients, especially if the patient is a young child, has limited mobility, dexterity or movement or has failing memory.

⁷ AIHW 2011. Projections of the incidence of treated end-stage kidney disease in Australia, 2010-2020. Cat. No. PHE 150. Canberra.

⁸ Kidney Health Australia, Chronic Kidney Disease Summit: The Need for Action in Australia, 2007. Available at <http://www.kidney.org.au/HealthProfessionals/PublicationsforHealthProfessionals/tabid/635/Default.aspx>.

Whilst the majority of Carers for dialysis patients believe their caring role is rewarding, caring is not always easy and comes at a cost. Carers have poorer health and well-being than non-Carers, and their responsibilities can adversely impact on family relationships, social networks, employment opportunities and finances.

Improving Access to a Support Payments

A carer payment is in general, defined by the Commonwealth to be a support payment for people who personally provide constant care in the home of someone with a severe disability, illness or is frail aged.

The Department of Human Services advised Kidney Health Australia that there are two separate streams for regular carers payments, in addition to an annual payment. Evaluation for eligibility takes into consideration number of hours the patient needs caring for, doctor recommendations, and the ability for a person to fend for themselves. The categories assessed fit within the activities of normal daily living.

As those in our kidney community understand it, dialysis is not uniformly considered a disability, frail aged or constant care illness as defined by the Department of Human Services⁹. However, assisting with dialysis can take 4-6 hours per day (minimum) which may preclude a dialysis carer from working. While on dialysis, the patient is essentially completely incapacitated, unable to walk or undertake any other activities and is therefore wholly reliant upon their carer. Following the completion of dialysis, they often feel ill, and if dialysis is undertaken in a hospital or satellite clinic, unable to drive – again requiring carer support.

There is also, an inconsistency in dialysis patients receiving carers financial support as in some rare cases it has been made available – potentially causing a disparity in outcomes nationally. Kidney Health Australia is therefore of the strong view that there can be changes made to the current eligibility requirements to allow for dialysis carers to access these payments. This is particularly important for those who are carers for patients on home haemodialysis – where the burden is greater.

There are also potential benefits for government to be gained from clarifying and standardising carer support for those facilitating home dialysis - home dialysis is on average \$30,000 per patient, per year, cheaper than dialysis undertaken in-centre, and reduces a significant burden on our health system.

The availability of a carer payment, restricted to the period of time on dialysis is likely to increase the uptake of home dialysis with its attendant saving in direct healthcare costs and its associated higher employment rate. Home dialysis allows patients to undertake nocturnal dialysis, delivering not only better health outcomes in some cases, but allowing them and their carer to potentially return to the workforce on a casual or part-time basis, where appropriate.

Conclusion

Kidney Health Australia welcomes to opportunity to provide a submission into this review. As the peak body representing those with kidney disease we urge the Australian Government to use the review to address a longstanding and inequitable approach to those who provide critical episodic carer roles, such as for those on dialysis, stemming for the non-full time, but highly intensive nature of dialysis.

⁹ <http://www.humanservices.gov.au/customer/enablers/centrelink/carers-allowance/eligibility>

These carers are critical in overcoming shortages in the provision of transport for those dialysing in-centre, and play a pivotal role in facilitating home dialysis which saves government funding, can provide better health outcomes and potentially facilitates their greater productivity in society. It should be recognised that home dialysis does place some cost burdens on the patient, and that with a currently inconsistent application of carer payments, can create a significant barrier to uptake and support, due to an inability of the system to accommodate episodic carers.