

## **Dialysis Education and Support**

**Project Title:** Kidney Health Australia – Dialysis Education and Support for People in Regional and Remote Areas of Australia.

**Applicant:** Kidney Health Australia

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## KHA's ask for funding support

Kidney Health Australia (KHA), the only national body dedicated to assisting Australians living with kidney disease to improve their health outcomes and quality of life, seeks government funding of \$1.5M establish and help deliver an education and support program for people living with CKD and being sustained by dialysis in regional and remote areas.

Funding will be directed to capacity building, to empower and leverage local communities, and to minimize the ongoing support costs.

## Patient population

In 2016 there were 12,706 people in Australia on dialysis. 2,714 commenced dialysis therapy in 2016. [1]Around 80% of these people live in major cities, 20% of these are located in inner regional areas, 8% in outer regional and 2% in remote or very remote areas. There are several possible explanations for the lower incidence of dialysis in rural areas. These include access to health care, with the related burden of travel to dialysis and choice of supportive care over active treatment.[2]

*Table 1. Numbers of people on dialysis in Australia*

Cohort	Number	Numbers by state							
		Australia	ACT	NSW	QLD	NT	SA	TAS	VIC
Dialysis	12706	287	3987	2376	636	806	229	3040	1345
Commencing Dialysis	2714	62	830	486	81	216	55	658	326

## Issues

### 1. Inadequacy and Inconsistency of Patient Education about Dialysis

People with end stage kidney disease (ESKD) need to absorb, understand and cope with a huge amount of information about their treatment and the necessary changes to their lifestyle. There is an extraordinary expectation for patients and care partners to carry out self-management and navigate complicated medical care, with little assistance from health providers. The need for effective and thorough patient education is more than any other chronic disease.

Most health services providing care to patients with reduced kidney function have some form of patient education, however the quality and quantity of education varies immensely by health service and by renal unit. A medical appointment offers only a small window of opportunity to discuss complex health queries and as a result, people often leave their health provider seeking additional information and support.

Kidney Health Australia consumer survey data [3] indicate there is variation in patient education practices across Victoria and Australia. Some inconsistencies were evident regarding: the method and delivery format; time devoted to education; the timing of information delivery; and the provision of information, such as dialysis type and location. [3,4]

## **2. Psychosocial Impact of Kidney Disease**

Life with kidney disease can be an isolating experience. As a result anxiety, depression and the inability to cope are very common in ESKD, contributing to poor health outcomes, hospitalization and death in this vulnerable group. This psychological distress is worst when patients first start dialysis, and face the reality of reduced quality of life and independence.

## **3. Inadequacy in healthcare for rural and remote Australians**

People living in rural areas of Australia have poorer health outcomes than those living in cities. Mortality rates in regional areas are higher than major cities and increase further with increasing remoteness [5]. Commencing dialysis in regional or remote areas of Australia is an independent predictor of mortality. This variation remains after correcting for the greater indigenous population in remote Australia. Possible explanations include access to health services and health care providers, physical inactivity, excess alcohol, poor nutrition, unemployment and lower socioeconomic status. Furthermore, rural residents undergo fewer diagnostic [6-8] or therapeutic interventions [9,10] than Australians in major cities.

The reduced access to healthcare services and providers in regional and remote areas of Australia heighten the education and information gap.

This isolation and psychosocial burden is exacerbated for people living in regional and remote areas of Australia.

## **KHA Proposal**

### **1 The Dialysis Nurse Educators Handbook**

Best practice in renal education has been defined in the Kidney Health Australia (KHA)-CARI guidelines [11] and the National Institute for Health and Care Excellence (NICE) guidelines.[12] These guidelines recommend that patient information is timely and tailored appropriately to patient preferences, cultural/social background, comorbid diseases, CKD stage, risk of progression, associated complications and treatment options. KHA's Kidney disease education pathway guidelines specify that education is a team responsibility and is not only required prior to the treatment journey but needs to be revisited throughout the patient's life.[13]

We propose a 'Dialysis Nurse Educators Handbook'. The development of this handbook will leverage Kidney Health Australia's experience with patient and health care professional education, in particular the gold standard 'Chronic Kidney Disease Management in General Practice' currently in its 3<sup>rd</sup> edition. Over 55,000 copies of the handbook have distributed to primary care health professionals and there have been over 5,400 downloads of the CKD management app 'CKD-Go!'.

The 'Dialysis Nurse Educators Handbook' will be developed using a similar process to our 'Chronic Kidney Disease Management in General Practice' handbook with an Education Advisory Committee. The handbook will contain links to relevant fact sheets, websites and additional resources are interspersed throughout. It will be available in both printed and electronic soft copies of the handbook.

The 'Dialysis Nurse Educators Handbook' will become the equivalent gold standard for dialysis education across Australia, ensuring dialysis education nurses deliver consistent and quality education.

### **2. Patient and Care Education**

To complement the 'Dialysis Nurse Educators Handbook' we propose all people who commence dialysis receive a 'Kidney Health Australia Patient Information Pack'. This will contain resources such as factsheets, information about how to access our website and the Kidney Helpline as well as information about local peer-to-peer support groups.

### **3. Patient and Carer Support**

To support and help people through the emotional journey of living with kidney disease, we propose to enhance and expand the Kidney Helpline to specifically cater for people commencing dialysis in particular to those living in rural and remote regions of Australia. The current service is beyond capacity and has no ability for additional call volume.

The current Kidney Health Australia Kidney Helpline is the only service that exists in Australia that has understanding of, or offers support for, kidney disease and currently responds to more than 2100 enquiries a year, without promotion of the service. The service provides information, support and referral advice relating to kidney health. It is often the case that the Kidney Helpline is the first point of human contact after diagnosis of kidney failure, helping people through the emotional journey of understanding kidney disease and its impact on lifestyle and family with practical information and pathway suggestions.

We also propose to build and implement a national peer support and education program for dialysis patients in regional and remote areas.

### Program Overview

Program element	Description	Costing comments
Establishment of Advisory Group	A group of key opinion leaders including renal nurses, nephrologists, social workers and psychologist, consumers and representatives from KHA	<i>To be undertaken by the project officer in collaboration with KHA clinical education team</i> <ul style="list-style-type: none"> <li>1 x Face to Face meeting</li> <li>5 Teleconferences in year 1</li> <li>2-3 x TC in additional years</li> </ul>
Dialysis Nurse Handbook	Handbook formalizing dialysis nurse education to patients	<i>To be undertaken by the project officer</i> <ul style="list-style-type: none"> <li>Review of current resources and guidelines</li> <li>Advisory group set up and consultation</li> <li>Development of handbook</li> <li>Design and Print</li> </ul>
Educational resources	Tailor existing resource and develop new ones, as required, in consultation with dialysis community  with capacity to be delivered in a variety of formats including video and app	<i>To be undertaken by the project officer in collaboration with KHA clinical education team</i> <ul style="list-style-type: none"> <li>Consult advisory group</li> <li>Development and production costs</li> </ul>
Kidney Helpline - telephone helpline	Augment existing service by expanding the current team and training all team members on how to manage and support calls dialysis patients who are isolated either by location or socially.	Cost of additional full time team member + training
Peer-to-peer support	Community Support Groups  Establish a secure and safe online forum on KHA’s upgraded website (scheduled to be delivered in Q4 2018)	<i>To be undertaken by the project officer working with the Kidney Health Australia Community team</i>  Addition costs associated with management and governance of community groups.

The benefits of this project will be measured by patient-reported health outcome measures (PROMs); including resilience and coping, psychological distress, quality of life, treatment adherence, care partner experience and self-management measures; and problems including hospitalization and home-based dialysis not being

## References

1. ANZDATA 40th Annual Report, 2017. Available at [http://www.anzdata.org.au/v1/annual\\_reports\\_download.html](http://www.anzdata.org.au/v1/annual_reports_download.html)
2. Gray N A, Dent H, McDonald S P. Renal replacement therapy in rural and urban Australia Nephrol Dial Transplant (2012) **27**: 2069–1969
3. Ludlow M, Lauder L, Mathew T, et al. 2012, Australian consumer perspectives on dialysis: First national census. Nephrology **17**: 703–709.
4. Fortnum D, Ludlow M, Morton RLR 2014, Renal unit characteristics and patient education practices that predict a high prevalence of home-based dialysis in Australia. Nephrology **19**: 587–593.
5. Australian Institute of Health and Welfare. Rural, Regional and Remote Health: a Study on Mortality (Summary of Findings). Canberra, Australia: AIHW, 2003. AIHWcat. no. PHE 49 (Rural Health Series no. 3)
6. Clark RA, Eckert KA, Stewart S et al. Rural and urban differentials in primary care management of chronic heart failure: new data from the CASE study. Med J Aust 2007; **186**: 441–445
7. Ewald DP, Eisman JA, Ewald BD et al. Population rates of bone densitometry use in Australia, 2001–2005, by sex and rural versus urban location. Med J Aust 2009; **190**: 126–128
8. Read SJ, Levy J. Differences in stroke care practices between regional and metropolitan hospitals. Intern Med J 2005; **35**: 447–450
9. Ng JQ, Hall SE, Holman CD et al. Inequalities in rural health care: differences in surgical intervention between metropolitan and rural Western Australia. ANZ J Surg 2005; **75**: 265–269
10. Clark RA, Driscoll A, Nottage J et al. Inequitable provision of optimal services for patients with chronic heart failure: a national geo-mapping study. Med J Aust 2007; **186**: 169–173
11. Atai E, Johnson D 2013, KHA-CARI guidelines: education strategies. Kidney Health Australia, South Melbourne.
12. National Institute for Health and Care Excellence 2014, Chronic kidney disease in adults: assessment and management, viewed 03 March 2018, <<http://www.nice.org.uk/guidance/cg182>>.
13. Fortnum D, Brown B, Maguire A, et al. 2015, Kidney disease education pathway guidelines 2014. The Home Network.