Improving health outcomes for adolescents and young adults with advanced kidney disease

Summary

Kidney Health Australia (KHA), the peak national body dedicated to helping Australians living with kidney disease, has received federal government funding until July 2020 to build and implement a national peer support and education program to engage and support the geographically dispersed population of around 500 young people (15-24 years) receiving renal replacement therapy.

KHA YOUTH will be co-designed by youth consumers, and funding will be directed to capacity building nationally so that the program will be largely self-sustaining.

The issue

Moving from paediatric to adult health care is challenging for young people, their families and health care workers. Apart from the normal developmental factors influencing young people, there are additional factors associated with having a chronic disease including:

- anger and resentment,
- denial of severity of illness,
- questioning authority leading to rejecting medical advice and treatment; and
- treatment in an adult clinic dominated by a significantly larger and older cohort with medical teams ill-equipped and under-resourced to tailor services to support younger patients.

Overview of KHA YOUTH

To assist young people and their carers navigate this challenging time it is recognised that there are a number of youth focused support services and resources that already exist, or have been trialed both here in Australia or in other countries.

KHA Youth aims to identify these successful, best practice approaches and design a complementary program to augment, support and share these nationally.

The major components of the program initially will therefore include:

- undertaking a national survey and state based focus groups with patients and carers to inform education initiatives (co-design) and encourage engagement in the program;
- multidisciplinary clinical consultation and research to inform, guide and support the program;
- designing an effective and efficient framework for delivery, engagement, support and evaluation of the identified key program activities.

This national consultation process and associated research will serve to underpin the proposed key activities within the program including:

- provision of peer support through a variety of mechanisms including face to face activities and virtual channels such as a secure and safe online forum;
developing and delivering training for staff and volunteers engaged in peer support programs;
developing and updating educational resources, in consultation with young adults, including provision of materials in different formats such as videos or apps;
expanding the Kidney Helpline and providing training to all team members on how to manage calls from young adults, their carers and family members; and
providing low cost social activities for young adults.

Program Outcomes

The expected outcomes of this program would be improved empowerment and engagement with their care and better patient outcomes through:

- reduced sense of isolation, increased sense of normality
- positive peer influence for study and employment
- improved body image
- dealing with independence for the first time.

KHA will collect baseline data and conduct follow up research to evaluate the impact of this program.

How to be involved

We have recently appointed Stephen Cornish as Youth Program Manager and he is based in the Kidney Health Australia Adelaide office.

Please contact Stephen directly to register your interest in KHA YOUTH and/or participating in the national consultation process.

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