

'Yarning Kidneys' Sessions to inform Indigenous Guidelines and the Aboriginal Kidney Care, Improving Outcomes Now Research

Ceduna, June 2019



Participants of the Ceduna community session shared with permission of all member

. Photo courtesy of The West Coast Sentinel

We talked to community and health care and service providers in Ceduna about their experiences with kidney disease and kidney care. These were the suggestions that people made;

- **Prevention**

- Prevention ought to focus on understanding and supporting people, no matter the circumstances or history and avoid a blaming approach.
- Educate young people about holistic wellbeing and how they can keep themselves healthy.

- **Early Detection**

- Teach people about what Chronic Kidney Disease is and the options available.
- Offer incentives for those who partake in kidney health checks.
- Give patients time to process information and make decisions, rather than rushing them into treatment.

- **Information and Education**

- Provide a regular time and space for meetings with health care and service providers, ensuring that this dialogue remains open.
- Provide education about treatment options such as peritoneal dialysis and help patients to dialyse at, or closer to, home.
- Ensure that interpreters and language appropriate educational materials are available.
- Provide education visually, using videos, pictures and by sharing peoples stories.
- Target some educational programs to the young people, but also ensure that community education programs are available and open to all.

- **Access**

- More housing options and improve long term housing in Ceduna for dialysis and renal patients.
- Provide consistently available transport services that can get people to and from their appointments.
- Seek housing options in Adelaide for patients who need to travel there for procedures and appointments.

-Improve the availability of holiday chairs and help to facilitate patient's travel or holiday plans and needs.

- **Cultural Safety**

- Create Aboriginal Health Practitioner roles within the hospital in Ceduna, specifically within the renal section, who are trained to provide dialysis.

- Support and assist patients to return to country on non-dialysis days, to engage with community and family and be involved in activities that can provide income.

- Seek reliable transport options that enable people to return home over the weekend but be back in Ceduna at the beginning of the week, in time for dialysis.

- **Transplant**

- Ensure Kangawodli is able to continue to support those that travel to Adelaide to receive transplant.

- Financially support transplant recipients to travel and ensure extra stress isn't created by facing out of pocket expenses.

- Support a family member to travel to Adelaide with the transplant recipient to provide them with social and emotional support.

- Ensure that interpreters are available for conversations pertaining to transplant.

- Give patients time to process their options and make decisions.

- **Additional Support**

- Provide patients with something to do whilst they are on dialysis such as colouring or painting.

- Hold regular community consultations and create a space for consumers and their families to give feedback about services.

- **The Role of Community, Strength and Empowerment – as described by community members**

- Keep strong for yourself and those around you, speaking up for yourself and your needs and helping others to do the same.

- Hold events that bring the community together to learn about keeping themselves healthy, such as cooking or health check days.

- Hold social events specifically for dialysis patients and their family and friends and support families to be more involved in the care.

These suggestions will be shared with Central and Northern Adelaide Renal and Transplantation Service, Kidney Health Australia, the KHA-CARI guidelines writing group and key stakeholders.

Where to Next?

- Provide Ceduna community and staff with feedback from the consultation.

- Send the report to the Indigenous Guidelines Writing group and the Government of Australia.

- Continue working with the aKction Reference Group and key stakeholders to address suggested changes.

For more information please contact;

- Dr Janet Kelly E :janet.kelly@adelaide.edu.au M:0428891286

- Dr Kim O'Donnell E: Kim.O'Donnell M:0407719568

- Ms Tahlee Stevenson E:Tahlee.Stevenson@adelaide.edu.au M:0411307297