

Government agrees to Medicare funding for assisted-dialysis in very remote Australia

At the Indigenous Patient Voices Symposium, we heard about the suffering and pressure patients and families experience when living away from home when a family member moves to town for life-saving haemodialysis.

Patients with a dialysis support buddy can learn to do haemodialysis and peritoneal dialysis by themselves. They can train in large cities, like Darwin, and then go home living well with home-dialysis.

But most patients need help by a nurse or health worker....

“I want it to get off the ground and have nurse supported haemodialysis at home, I would like to go home, it is better than here. I thank you all, the doctors that have helped me with the dialysis.” Quoted from Indigenous Patient Voices Symposium

We know dialysis assisted by a health worker or nurse in remote Australia is successful and safe. This has been the experience of the Tiwi Island Dialysis unit, which was the first health worker and nurse assisted dialysis unit in very remote Australia, which opened in 1999.

Along with many other people, I strongly recommended the federal government provide Medicare funding so patients and families can have dialysis care close to home with assistance by nurses or health workers. This funding mechanism never existed before through the federal Department of Health. It meant many people were stuck in town.

CONGRATULATIONS TO OUR FAMILIES AND COMMUNITIES

The Federal Government announced on 29th April 2018 ...from 1st November 2018, Medicare will fund dialysis assisted by a nurse, Aboriginal health worker or Aboriginal health practitioner for people living in very remote Australia.

Report (Nephrology journal website):

<http://onlinelibrary.wiley.com/doi/10.1111/nep.2018.23.issue-S1/issuetoc>

Symposium videos (Menzies website): <http://bit.ly/2zBw4ol>

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Key Themes from the Indigenous Patient Voices Symposium Report

- Respect
- Information and Education
- Kidney Care close to home
- Access to specialist treatments including transplantation
- Workforce enhancement- building a culturally safe workforce and valuing and building Aboriginal and Torres Strait Islander people in the kidney workforce

The Report includes a detailed Call to Action to drive change at local, state, Territory and Federal levels.

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Catching Some AIR- Asserting Indigenous Information Rights in Renal Disease

The *Catching Some Air* project team is based at Menzies School of Health Research in Darwin and has been funded during 2017-2019 by the Lowijta Institute. *Catching Some Air* will gather recommendations from the Aboriginal and Torres Strait Islander kidney health community in Darwin, Thursday Island and Alice Springs about the design and development of best practice and community-informed guidelines for:

1. Indigenous Data Governance Framework for Aboriginal and Torres Strait Islander data within the Australian and New Zealand Dialysis and Transplantation Registry (ANZDATA);
2. Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) Guideline for the Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander peoples.

Key feedback from the Darwin meeting (April 23-24th 2018) included

1. Clinical care for kidney health is so strongly linked with kidney information and data
2. Information about kidney illness, the people and families impacted by kidney disease are very important knowledge that should be used and made available to patients, families, communities and health services.
3. Partnering in health should also include Aboriginal and Torres Strait Islander patients and communities, to create the best kidney health policy, health services design and support best use of data.
4. We made a brief video found here <https://vimeo.com/267732848>

Thanks to...

- Darwin meeting technical experts:
 - Mr Lachlan Ross (Top-End Renal Advisory and Advocacy Committee) and
 - Dr Lisa Murphy (interim Chief Executive Officer Kidney Health Australia)
- Those who share important kidney health news in our communities
 - BBM987 Cairns -National Indigenous Radio Service broadcasting, 26th April 2018
 - Christine West, Top-End Renal Services dietitian for the feature story in the May-June TERS Renal Patient Newsletter
 - “TEHS Postcards” for the May postcards feature.



Photos: Left, Phillip Mills (meeting facilitator), Lachlan Ross (expert advisor), Cathie Nickels (patient delegate); Middle, Dr William Majoni & Mr Craig Castillon (from Top-End Health Services); Right: Dr Jaqui Hughes, Dr Lisa Murphy (expert advisors)

Thankyou

Please share this newsletter with your community and health service leaders so they know they have your support to drive change and build the best health care systems for all Australians. This newsletter was produced by Dr Hughes, as part of the *Catching Some Air –Asserting Indigenous Information Rights in Renal Disease* project. Follow our yarns and information sharing on twitter with #CatchingSomeAir