

# Remote possibilities: from a Pintupi dream to Medicare funding

Sarah Brown

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In May, I found myself locked in a room in Canberra, surrounded by suited bureaucrats, quietly buzzing about the room. It was Federal Budget night and I'd been invited to attend the 'lock-up'. I knew it *had* to be a positive sign but didn't want to count my chickens. The bureaucrats sat quietly beside me, mostly, to make sure I behaved (I'd threatened to put my undies on my head if I got good news).

It turns out they had reason to worry such a scene might occur. That night Minister for Indigenous Health, Ken Wyatt, announced a significant increase in core funding for Purple House, the Indigenous-led and run health organisation based in a small suburban house in Alice Springs, which I've had the privilege of steering for over 15 years.

Then came even bigger news. From November 2018 there would be a new Medicare Benefits Schedule item number for dialysis treatment in a very remote location by a nurse or Aboriginal health practitioner.

## Boom!

Many people might say, "So what?"; others ask, "Wasn't there one already?"

To help put this in context and to explain what a miracle of community determination this moment represented, we need to go back a bit.

Think desert. Think Western Desert. Think of the remotest communities in Australia, communities of seventy to a couple of hundred people. People with a long, proud history of flourishing in harsh country, looking after sacred sites and each other.

Non-Aboriginal people came late to this country, a mix of missionaries and government officials with clear ideas of what was best for people. Forced off their country to sit in artificially created communities to receive rations and welfare, people like the Pintupi were miserable, sick and worried for their country.

They lobbied and fought to get home. Walungurru (Kintore) community in the Northern Territory was established in 1981 and Kiwirrkurra in Western Australia, in 1983. People were so happy to be home. They had their art centre, they were painting their stories and making money, they were hunting and looking after sacred sites. They were teaching their children their cultural heritage. They were doing the best they could with what they had, to adapt to the rapidly changing world around them.

And then, people started to get sick. This was a new sickness. The doctors were telling senior people they had kidney disease. That they would have to leave their families and country to be in Alice Springs, to be hooked up to a machine in the hospital and have their blood cleaned three times each week, for ever.

Some people made the move, many hundreds of kilometres from their homes. With little English, no social support and few resources to advocate for themselves, they came. But they were miserable, doing really poorly and in the words of Pintupi leader Smithy Zimran, were "living like dogs on the fringes of Alice, waiting for their next dialysis and waiting to die". They had the worst survival statistics on dialysis in the country.

So Mr Zimran and others began to ask, "Why can't we have a dialysis machine in Kintore and then people can go home and family can look after us?"

There was no support from politicians or the health departments at the time. So, together with their art centre, Papunya Tula Artists, Sotheby's auction house and curator Hetti Perkins from the Art Gallery of NSW, they painted some *incredibly* beautiful paintings. The paintings were auctioned at the Art Gallery of NSW in November 2000 and raised over a million dollars in a single night.

It was a million dollars of independent money, not government money. This was their chance. A chance to create their own model of care. A model that was safe, sustainable, with cultural

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priorities at the front and centre. It needed to be community-controlled, with real ownership.

And so in 2003, the Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation was born, with an all-Indigenous board. It began with just one machine in the back bedroom of a suburban house in Alice Springs and a second machine at the clinic in Kintore, 550 kilometres west. And even just a whiff of time on country improved people's health. We found ways to take the hard edges off the system. We gave people hope and we started getting them home.

The little house in Alice was painted purple (why not?). People began calling it "the Purple House" and it grew to become more than just a place to get dialysis. It became a place to bring your family, meet new friends, cook a kangaroo tail, make a batch of bush medicine and do your washing. We got chickens for the yard, installed a pizza oven, established a GP clinic, offered podiatry, played music, danced. Our bosses out bush insisted that it be a place where everyone is welcome, but that sugar, soft drinks, and junk food is not. We attracted great staff. People who are keen to learn and share, and to be part of something fantastic. We created a place based on unconditional love, family and compassion.

As Marlene Nampitjinpa Spencer, our vice-chairperson, wrote about working for the Purple House: "It is really important for workers to be kind, friendly and gentle. They need to care about doing a good job. It's not about the money. You need to be straight and honest and look after people. Talk to them and look after them — not be selfish and mean. We are all helping one another and working together... Sharing story — Aboriginal way — listening to what people are saying."

"We are proud of it. This Purple House is like a home. It is a moving spirit. It is a special place for people. *Kurunpa* (spirit) is moving in the Purple House, it is part of the Purple House," she said.

Word spread across communities and we started to get calls from other language groups asking for help. Pintupi are compassionate and generous and are eager to help them,



even though they were far from having dialysis in all their own communities.

Today we have dialysis six days a week in 14 communities across the Northern Territory and in Western Australia. We are building clinics in four more communities including Pukatja (Ernabella), which will be our first South Australian service. We now have a drop-in centre in Darwin and a nurse who works for us in Perth. We've also got the Purple Truck, which has been on the road for seven years with not a cent of government funding. We have a bush medicine social enterprise; we provide aged care and NDIS services. There are no afternoon snoozes around here any more!

We continue to raise funds (we love Rotary clubs!), attract volunteers, students and people from around the country and overseas who we suck into the Purple House vortex of general wonderfulness. We attract dialysis nurses who are keen to work for and with Aboriginal people and want the opportunity to be part of a supportive organisation, low in unnecessary bureaucracy but high in ethical values and fabulous care.

In return, our directors and patients put high value on looking after staff, each other and sucking the juice out of every day.

So there I was, in a room full of suits and ties in the Federal Budget lock-up in Canberra. I sat there thinking about all the years we just haven't fitted in here. Dialysis traditionally has been seen as hospital business. We are no hospital. In the face of contracting Territory and Commonwealth health budgets, each few years we found ourselves fighting for our very existence. There had to be a better way. Because the





statistics spoke for themselves. They were showing improved life expectancy, reduced hospitalisations, better attendance rates for people who got back home, even for just part of the year. Hope is a powerful force. So, when Medicare was to be reviewed, brave and fearless friends in high places put forward the idea of an item number for a remote dialysis. **BRILLIANT!** It would be a source of funding that would not change with whoever was in government. It would mean the funding would follow the patient and that communities could help us with infrastructure, knowing we would have enough money to keep the doors open. We are certainly not short of people wanting to be home with their families on country. It would be based on our model of care, but available to the whole of remote Australia!

Now, you might understand my excitement (and the joyous threat to wear my knickers on my head) when the Medicare item number was finally announced! This, this would change everything.

## So, what now?

As you can imagine, we are planning on making the most of this opportunity. In April next year we are hoping to organise a meeting in Alice Springs of people who are interested in what we do and how we got here. A Purple House love-in, cross-cultural extravaganza (or conference if you want to be boring). Get in touch if you'd like to be on the mailing list for updates.

We are always keen to hear from nurses and Aboriginal health practitioners interested in coming to work for us or even checking us out to see what you think and we love people to follow us on Facebook, Instagram or Twitter! Basically, we love making connections, friends, and sharing our story ... Come on, we dare you!

So, on the eve of the new Medicare funding, I find myself thinking a lot about a letter that the Purple House directors wrote to Minister Ken Wyatt early this year. A letter that was written before we knew about the new funding. He has mentioned this letter many times subsequently and the impact it had on him. Perhaps it will have an impact on you too.

*We started our organisation ourselves. This is because it is so important to us to look after our family members on dialysis*

*and help them to get home. We know they do much better on country. They are important members of the community who hold vital cultural knowledge and MUST be on country to teach their grandkids the right way.*

*We hold people close and we help them to have the best life they can.*

*Together with our patient preceptors, our nurses and us as directors we work with our communities to demystify dialysis, to encourage wise decisions in our communities about health and to make plans for the future. We give people hope.*

*Traditionally kidneys hold the spirit ... the kurrumpa. Our spirits are kept strong through connection to family and country and by doing things the right way.*

*We struggle when governments tell us that our work does not fit. That dialysis is hospital business or when they don't understand what we are trying to do.*

*The dialysis machine for us is a **tool**. It is a tool to get people home, to keep them well, to give them an opportunity to look after their country and lead their communities.*

*We will push on, people cannot wait. We work hard to take our part in making sure that our grandkids don't get this horrible disease.*

*In 1985, in our community of Kiwirrkurra, people walked in from the desert having never seen whitefellas. It seems like yesterday. We run our clinic, we look after our country, we paint and share our stories, we adapt to the changes happening around us. But we need time. We know that whatever we do, some people are going to get sick with kidney disease. We must work to make this number of people smaller, to slow down the trip to dialysis for those who have kidney problems and to get those people on dialysis home on the machine or with a transplant. We must do all of these things together. We can't do one and not the others.*

*We don't see state and territory borders. We see people who need to be home to keep their families and communities strong.*

*We have learnt lots about good care, good communication, good governance and good outcomes over the years. We welcome an opportunity to share this story with you and other communities.*

*Walytja, (family) Ngurra, (Country) Tjukurrpa, (Dreaming) Kuunyi (Compassion).*

*These are the important things.*

*PALYA! Thank you.*

Purple House

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# WHY MANAGE THE RISK WHEN WE CAN REDUCE IT?

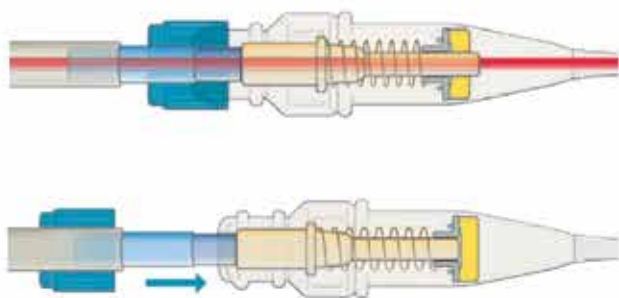


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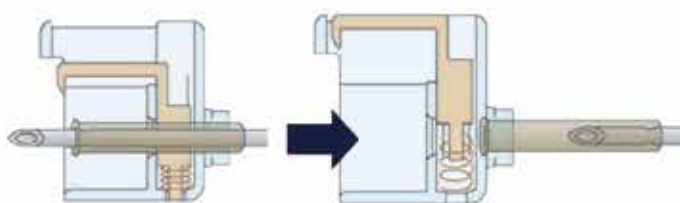


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## Antimicrobial Catheter Lock Solutions

### The requirements of antimicrobial catheter lock solutions:

### What should they do and what can they do?

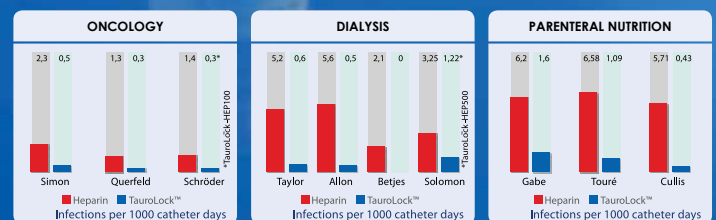
Catheter lock solutions are instilled into central venous access systems to have certain effects in this location. These access systems can be either dialysis catheters, Hickman- type lines or port-a-cath systems. The latter are used mainly in parenteral nutrition and for the administration of medication in oncology patients. These access systems are approved as medical devices and are CE marked. The central venous access is inserted in the subclavian, jugular or femoral veins.

The use of Antimicrobial Lock Solutions have been recommended in the "Hygiene Guideline complementing the German Dialysis Standard" and in the Position statement of European Renal Best Practice (ERBP)". Pure heparin solutions containing no antimicrobial agent do not meet this criterion. Antibiotics are associated with the development of resistancy which is a major drawback. Highly concentrated citrate solutions and taurolidine-citrate solutions are therefore conceivably useful in this application.

Highly concentrated citrate solutions (30% and 46.7%) cause major adverse effects such as cardiac arrests and embolisms that are a significant risk for the patient. **TauroLock™** as an antimicrobial lock solution has proven useful in dialysis, oncology and parenteral nutrition for many years and has meanwhile become established in the prevention of catheter-related infections.



### TauroLock™ prevents catheter infections:



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\* Punt, C.D., Boer, W.E. Cardiac arrest following injection of concentrated trisodium citrate, *Clinical Nephrology*, 2008, 69: 117-118. \*\* Willicombe, M.K., Vernon, K., Davenport, A. Embolic Complications From Central Venous Hemodialysis Catheters: Used With Hypertonic Citrate Locking Solutions. *American Journal of Kidney Diseases*, 2010, 55: pp 348 - 351. \*\*\* Polaschegg, H.-D., Sodemann, K. Risks related to catheter locking solutions containing concentrated citrate. *Nephrol. Dial. Transplant.* 2003, 18: 2688-2690. \*\*\*\* Schilcher, G. Polaschegg H.D. et al. Hypertonic Trisodium Citrate Induces Protein Precipitation in Hemodialysis Catheters. *Selected ASN Meeting Abstracts*, 2011

# Renal Nutrition, Nursing and Allied Health Professionals Symposium

A joint symposium of ISN Renal Health Professionals Working Group (ISN RHP WG) and International Society of Renal Nutrition and Metabolism (ISRNM)

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