



Emergency dialysis in central Australia

The Australian Greens believe the need for dialysis services in Alice Springs is a matter of extreme urgency and warrants debate here today. We are currently facing a crisis in Central Australia regarding the provision of healthcare services and support for Aboriginal patients requiring renal dialysis. The Northern Territory government has recently announced that, effectively, it is closing its borders to new interstate dialysis patients from the border regions of South Australia and Western Australia, my home state. New patients seeking these services are being turned away because of a serious shortfall in dialysis places, sometimes called 'beds' or 'seats' in Alice Springs. The Alice Springs renal dialysis unit, the RDU, with 26 dialysis stations, is currently the largest in the Southern Hemisphere, but it is currently 20 per cent over capacity. A new \$16.7 million, 12-station renal unit is under construction and is due to open in April 2010-although the latest news is that this date may have been pushed out to June this year or even beyond.

This unit has been designed to be more user-friendly to the large and growing number of Aboriginal patients requiring dialysis, and their families. When it comes on line, which may not be for six months or longer, it should deal with the current unmet need and give us a bit of breathing space. But we know that the level of kidney failure and the need for acute health services in the Aboriginal population continue to grow at an alarming rate. This means we need to think about planning and building the next one, two, three or more renal dialysis units in Central Australia. We need a comprehensive strategy to plan for the future, based on an analysis of the location and scale of this growing demand. We need a better understanding of the factors that lead to higher rates of end-stage kidney failure among Aboriginal Australians and an investment of significant resources into prevention and early intervention. We need to reduce the growing burden of chronic disease on our healthcare system.

This is not a sudden crisis. We have known about and been alarmed about the growing rate of kidney disease in Central Australia for some time. The establishment of the renal dialysis unit in Alice Springs and the current construction of the new unit on Gap Road show that effort is being made to meet this growing demand-and of course we commend this investment-but, unfortunately, too much of this effort has been a struggle to catch up with unmet demand rather than a planned response to the projected need. The Commonwealth government has been aware of the problem of meeting growing demand for renal kidney dialysis for some time. In the 2006-07 annual report of the Department of Health and Ageing, Australia's Chief Medical Officer at the time, Professor John Horvath, had this to say:

Another area that has been a challenge is the delivery of renal dialysis services to many patient groups, especially in Central Australia. Patient numbers threaten to overwhelm the capacity of the staff and facilities to deliver services, and there is a need to have these services much closer to the communities. In September 2006, I convened a meeting of all interested clinicians in Central Australia and we had a highly productive roundtable in Alice Springs. As a result, there has been a lot of progress and the Department is working with the Northern Territory, South Australian and Western Australian health departments to expand and improve current models of service delivery and care for renal patients.

While it is true that we now have a new medical officer, Professor Jim Bishop, I note that Professor Horvath very clearly said that the department was working with the health departments of the Northern Territory, Western Australia and South Australia to undertake this expansion and improvement. I am hoping that during the debate today government senators will be able to give us an update on what efforts are being made and the progress in these efforts.

I note that, when we discussed these issues earlier this week, I was told by various people from the government that this is a state problem-and it needs to be resolved by the state and the Northern Territory-rather than a Commonwealth issue. I have been told that it is not the responsibility of the



Commonwealth to try to find an outcome to this problem. I note that this appears to be at odds with the comments in the 2006-07 annual report, which also highlights the fact that the Commonwealth has taken a keen interest. I will note that the Commonwealth contributes resources to fund various aspects of renal disease treatments and dialysis.

It also appears to be at odds with the commitment made by the Rudd government to close the gap on Aboriginal health, disadvantage and life expectancy. It also appears to be at odds with the Prime Minister's statements in the lead-up to the last election that if the states and territories could not sort their problems with hospitals and health care, then he would step in and take over. It also appears to be at odds with the intent of the current consultation process with Aboriginal communities, which has been unfortunately described to me by some in the Northern Territory as a sort of 'speed dating'. When communities were asked about their problems, concerns and priority needs, chronic health problems and access to dialysis for their elders come top of the list. I would ask the Senate to consider these points while I am giving some background to this issue and telling some stories for the Northern Territory so that this becomes real to people-the real impact on real people.

I would dearly love an explanation from the federal government about why they do not think this is also their responsibility. This is a responsibility for the federal government, the state governments of Western Australia and South Australia and the Northern Territory government. They could also perhaps explain what the purpose is of closing the gap. Is it to ensure that people do get access to quality healthcare services? For people living in the western desert communities near the WA and Northern Territory border, and for those in communities in the APY Lands near the South Australia-NT border, Alice Springs is very much their regional centre and it has been for a long time. The lines imposed on the map do not reflect the cultural make-up of the region. In many instances they share languages and culture and have close cultural ties. Kiwirrkurra is located just inside the Northern Territory border. It is 2,400 kilometres from Perth-the city in which I live-and there is no road direct from there to Perth.

If you were going to re-do the map, it is highly likely that there would be a circle around Central Australia. The current lines on the map for Central Australia are arbitrary lines, and people in Central Australia and certainly in the western areas of Western Australia do not see Perth as their centre. Nor in South Australia do they see Adelaide as their centre. It does not make sense to be denying people who are chronically ill access to urgently needed medical services on the basis of state lines. If I am taken ill or collapse in the street here in Canberra, I would not expect to be refused service and told to go home to Perth to get those services, yet that is essentially what we are telling Aboriginal Australians.

I would like to tell Patrick Tjungurrayi's story. He is a renowned member of the Papunya Tula group of artists. Last year, Patrick won Australia's richest Aboriginal art prize: the \$50,000 WA Indigenous art award. Nine years ago, in the year 2000, Patrick and his fellow artists from the western desert region held an auction at a New South Wales gallery which raised \$1 million to set up services, including the Kintore dialysis centre and the dialysis training house in Alice Springs, known as 'the purple house'. I know that a number of my fellow senators in this chamber have visited the purple house on numerous occasions. The Kiwirrkurra painting that was painted by Patrick and others from his home town was bought by Kerry Stokes for \$340,000, helping to pay for the Kintore dialysis unit.

Now, nine years later, at the age of 70, Patrick finds himself in urgent need of renal services. He has been denied access to services in Alice Springs. He was initially told to go to Kalgoorlie-again in my home state of Western Australia-to which there is no direct route, but that service was full, so he was then told he would have to go to Perth. Kiwirrkurra is 40 kilometres from the Northern Territory border, 150 kilometres or so from Kintore and 550 kilometres from Alice Springs. It is 2,400 kilometres, as the crow flies, from Perth. There are no road or air links between Kiwirrkurra and Perth-or, in fact, Kalgoorlie. To get to either place he must travel through-you got it!-Alice Springs. Alice Springs is Patrick's regional centre. He speaks the languages spoken by many of his community who are already in Alice Springs.

Patrick will not go to Perth, because it is a strange place where he knows his family will not be able to visit him. He will probably need to remain on regular dialysis for the rest of his life, meaning that it



could effectively be, unfortunately, his permanent home. He fears he will be going away to die alone-far from his land, his family and his community. Because the NT government are now denying 'outsiders' access to all renal services, Patrick is unable to access the dialysis unit in Kintore that he helped to fund. The ban was meant to be just about the shortage of dialysis machines, but the NT are now also apparently stopping any access to renal services, including renal check-ups, discussion of treatment options, health management plans and access to simple preparatory operations, like getting a fistula fitted. Patrick had a doctor's check-up at Kiwirrkurra and was referred to the nephrologist-the kidney doctor-in Alice Springs to have an assessment done, discuss treatment options and get a fistula fitted. That was when the problems started and he was told to go to Kalgoorlie or Perth. Patrick needs access to a renal doctor and a management plan now.

I should have said at the outset that I have permission to tell Patrick's story. Patrick's GFR-his test for kidney function-is currently 40. At a reading of 60, you get a management plan. At 30, you fit a fistula and you develop a plan for dialysis. At 15, you should go on dialysis. Before Patrick can access the renal facility near to his home at Kintore, he needs to have a simple operation to fit the fistula and then to undergo his first dialysis in hospital and to stabilise his condition. He can only use the facilities, for which I again note he helped pay, at Kintore or the Purple House in Alice Springs under joint management-that is, under the supervision of the nephrologist from Alice Springs Hospital and a renal nurse. The doctor would have to be satisfied his condition was stable enough and that he was healthy enough to be far away from hospital.

It is possible that there might be other options for treating Patrick. For instance, he might be able to use peritoneal dialysis, which is a tube into the stomach, rather than haemodialysis. Peritoneal dialysis is cheaper and easier and does not require the use of a big dialysis machine. Patients can plug into a smaller box overnight. Peritoneal dialysis as a treatment option is underused in Central Australia. I would ask the question: why? The point here is that we do not know if Patrick would be able to use that sort of treatment because he has not been able to access Alice Springs and he has been denied access to the experts in Alice Springs.

I would like to read a letter that I have received from Papunya Tula about this issue of dialysis. It says:

On behalf of Patrick Tjungurrayi and the Papunya Tula Artists I would like to send you a short message of thanks for helping us highlight the situation surrounding Patrick, and several other renal failure sufferers in central Australia, to the parliament and the general public.

It really seems terribly unjust that someone's life can be dealt with in such a manner when we all know that Patrick would not consider for a minute a move to Kalgoorlie or, worse, to Perth to receive treatment. In other words his fate would be sealed and he would be resigned to a premature death in Kiwirrkura. Patrick is one of the most successful and well known Papunya Tula artists and last year won one of Australia's most prestigious art awards-the Western Australian Indigenous Art Award. He is a senior Pintupi custodian and a vitally important cultural figure within the Western Desert community.

I have worked at Papunya Tula artists, of which Patrick is a shareholder, for the last fifteen years. In this time I have known no fewer than twelve people who have died as a result of end stage renal failure. Many of these people were senior members of the Kintore and Kiwirrkura community's and important Australian artists. It was this situation that initially led us to privately fund our own dialysis facilities in Kintore through a fund raising event in Sydney nine years ago that raised over a million dollars. The unit is a shining model of success and is currently an essential component of the dialysis programme for people from the Kintore area by allowing them to continue receiving treatment while on respite visits to their homeland. The tragic irony of this situation is that Patrick was one of the main contributors to the initial fund raiser by overseeing the collaborative painting done by the Kiwirrkura men that went on to raise \$300,000.00 and now he is unable to access the facilities resulting from his effort.

I know you are probably aware of the above information, but again, thanks very much for your



concern it's very much appreciated.

(Other Senators speak)

Because a man lives 40 kilometres to the wrong side of the border, he has been denied access to dialysis. That is an unacceptable situation in this country. He has been denied access at his nearest centre in the Northern Territory. He would have to fly 2,400 kilometres. He does not see that as a solution. He sees that he would in fact pass away in land that is not in his country. In other words, he is offered no solution to his health problems. That is an unacceptable situation in 2009, in what we call the lucky country. Governments across Australia are committed to closing the gap-the federal government, the Territory government and the state governments involved-and yet here we have patients that have no access to dialysis. As I said, that is unacceptable.

Yes, Senator Adams mentioned the meeting of health ministers that was held last week. One would think they would have discussed access to short-term dialysis to fix this problem while the beds come on in the longer term, but apparently they did not. I heard that from Dr Kim Hames, who is the Minister for Health in Western Australia, on the radio last night. They discussed the longer term provision of dialysis units in Western Australia, South Australia and the NT, I understand. But they did not discuss this short-term crisis. I find that, quite frankly, unbelievable.

I must admit that two weeks ago when I heard the announcement from Minister Snowdon that a temporary unit of two new beds was going to be housed in Alice Springs I thought: 'Fantastic. That was one of the shortest campaigns we have had to run. We have dealt with this issue of the ban in the Northern Territory because two more beds have been provided and that will get us over the hump until the new beds in Alice Springs have come online.' But I was sadly mistaken. What Senator Crossin did not articulate in her speech was that the Northern Territory government has not lifted the ban on interstate patients. So the government can crow all that it likes about the fact that it has provided two new beds; it has met some of the unmet need in the Northern Territory, but not for Western Australia and not for South Australia. As of this morning Patrick has still be refused access to renal services in Alice Springs. I will reiterate: that is unacceptable in 2009.

Are we going to stand by and watch patients be denied access to dialysis? No, we should not. If we are genuinely committed to closing the gap, no, we should not. The Commonwealth, as Senator Crossin articulated, has put \$1.6 billion into Indigenous health and yet we cannot provide dialysis for patients in Central Australia. That is unacceptable.

What could be done in the short term, as Senator Adams commented, is nocturnal dialysis. This of course is not a long-term option but for the short term isn't it better than nothing? Isn't it better than people dying on country without access to the vital services they need to save their lives. Of course it is an option. The Commonwealth has pumped millions and millions and millions of dollars into the Northern Territory intervention to deal with the emergency. Is this not an emergency? Here we are getting caught up, yet again, in arguments between what is a federal, state or territory responsibility. When are we going to get over it? It is not good enough that people will die without this treatment. They have been told to fly over 2,000 kilometres away from their homes and away from their families. It is another form of denial of services. People are being sent to Adelaide. We were just told that the South Australian government is looking at providing more beds in Adelaide. If you live on the APY lands you are being sent to Adelaide. Again: away from your home, away from your family, away from your culture and away from your land. That is not acceptable either. That does not go towards closing the gap.

We believe that the Commonwealth has a fundamental responsibility to show some leadership here. If the states and territories appear incapable of solving this shortfall the Commonwealth needs to show leadership. They have shown leadership before- (Time expired)

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