

Congress of Older People's Voices from the Margins

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Dialysis and older men, by Max Primmer

My name is Max Primmer, and I've been down the dialysis path. I was on renal dialysis in 2009 after my kidneys failed overnight. I was on dialysis for three years. For me it was something that just had to be done. I didn't say 'why me' – that's not part of my character. I am a positive person. I just got on with it and focused on the fact that I was still alive.

In 2012, I was fortunate to have a kidney transplant. I got a call one day to say there was a kidney for me. That was one of the happiest days of my life. I am so grateful for the second chance at life and very aware of the beautiful generosity of my kidney donor and every person that donates their organs.

Since I had the transplant, I volunteer at the local dialysis unit. I've been doing that every week for seven years. I am also on call if they have a new patient or someone who needs a chat.

Chronic kidney disease is more common than most people think. The prevalence increases rapidly with age, affecting around 44% of Australians aged 75+. The number has doubled and the number of hospitalisations for dialysis has tripled - around 14% of hospitalisations are for dialysis. Dialysis costs around \$85-\$125,000 per person per year.

Indigenous Australians are hospitalised for dialysis at a rate over 10 times as high as that for non-Indigenous Australians and are almost four times as likely to die with chronic kidney disease as a cause.

For people on dialysis there are high rates of mental health issues and poor quality of life. The research also shows that although twice as many women than men on dialysis are diagnosed with depression, twice as many men than women suicide.

Men more often adopt avoidance as a coping strategy and can find it difficult to express their fears in response to the social pressure or expectation of them being tough, strong, and responsible for the economy of the household.

This is the point I want to highlight in my presentation. Older men have a different experience of dialysis, they can be marginalised by their mental health issues and the lack of information on how to adjust when they need dialysis.

The stuff that is tough for men of a certain age is that they are used to expressing their masculinity in a particular way. Some have been the bread winner their whole life and suddenly, they aren't. They can't do that role anymore. They feel weak. Some feel emasculated. It affects their masculinity; they might not be sure who they are anymore. That's where the mental health issues from.

A lot of old men on dialysis that I have spoken to are in hospital for dialysis on a Monday morning and have to go back on the Wednesday. They get depressed about that and so they end up having a drink. I mean grog. They are being told what to do by someone they don't know. And they don't like what they are being told. They don't like the adjustments and the restrictions that they have to make.

People on dialysis are told what they can eat and what they can drink. For some people this is a significant adjustment, on top of spending a lot of time in hospital in the dialysis unit.

I love hospital food, someone brings it to you and then takes it away and does the dishes. I know it's not high class, but you just have to get on with it. But some of the men fight it. Their mind tells them they shouldn't be there. They don't want to be there, and they fight it.

They find it difficult to be told they need to be on a salt free diet. For the older men who have been bought up on meat and three veg and they don't want to do it, so they won't. That puts pressure on their partner because they want to cook the special food that gives their partner the best chance at life, but the patient won't eat it. Some of the older men I know think their life is over and they decided not to comply, and they go home and die.

Some find it difficult to be told to be careful how much fluid they can have. You get weighed every time you go to dialysis and your weight dictates how long you have to have dialysis for. If you have played up and not done the right thing, you have to stay in dialysis longer. Some people are there for five hours. They can't get their heads around it. It's really hard for them. They think they have been alright for 60 years, why do I have to change now?

Not enough people are donating their organs, so getting a kidney transplant is difficult and the reality is a lot of older men will need to be on dialysis for a very long time. Some think, I'm not doing this for 10 years; I would rather be dead.

We need to give older men information, education and support to help them adjust. They are not genderless. We can relieve the distress for them and for their families. I'm not saying it's not difficult for women or anyone who is on dialysis – what I am saying is, we need to understand the role of gender in supporting adjustment to dialysis and in helping people understand kidney health as they age.

What's one thing people can do now? Talk to your doctor about your kidneys and how you can look after them and become an organ donor.

