

Deceased Organ Donation Review
Sector and Services Policy
Ministry of Health
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Rural Women New Zealand

Submission on ‘Increasing rates of deceased organ donation’ Consultation document

Introduction to Rural Women New Zealand

1. Rural Women New Zealand (“RWNZ”) is a not-for-profit member based organisation that reaches into all rural communities and advocates on issues that impact on those communities. We welcome the opportunity to provide a submission to the Ministry of Health (“the Ministry”) on its consultation document ‘Increasing rates of deceased organ donation’.

Overview of our submission

2. RWNZ strongly support the development of a national strategy to increase deceased organ donations in New Zealand. The growing number of people living with organ failure, coupled with New Zealand’s low rates of organ donation is an issue which we consider warrants urgent government attention and a well thought out strategic approach.
3. Failure by the Government to act effectively on this issue has a real and human impact for those New Zealanders who are living with organ failure today and who are desperately waiting for their opportunity to receive a second chance of life. The quality of life consequences of sitting on a donor waiting list are incredibly tough. For those in rural areas, the challenges of needing to seek ongoing treatment for organ failure are further compounded by issues with access to healthcare in these areas. In this submission we provide first hand experiences from our members to illustrate this point.
4. From this perspective, we are very disappointed that the option of establishing a fully functional donor register appears to have been sidelined in the paper. In our view, the current drivers license system is simply not working. Under this system, families do (and are very likely to) overturn the wishes of the deceased because they have not been involved in the initial process of obtaining the deceased’s consent. As noted in the paper there is also a strong reluctance by clinicians to treat this form of consent as medically informed.
5. RWNZ feel strongly that the Government needs to invest in a registration system that is available to all New Zealanders, that facilitates consultation with family and that provides for fully informed consent within an appropriate medical setting. We expand on these points below and provide further comments on other points of relevance to rural New Zealand.

Support Government focus on increasing rates on organ donation

6. RWNZ strongly support the development of a national strategy to increase deceased organ donations in New Zealand. The growing number of people living with organ failure, coupled with New Zealand's low rates of organ donation is an issue which we consider warrants urgent government attention and a well thought out strategic approach. Failure by the government to act on this issue, has significant quality of life consequences for those who are living with organ failure today and who are desperately waiting for their opportunity to receive a second chance of life.
7. The consequences of sitting on a donor waiting list are particularly tough for those in rural areas. Access to treatment options like dialysis is limited in these parts of the country and individuals and their families will often need to travel long distances at considerable expense and disruption to family life.

When my late husband was first on dialysis we had to travel from Cromwell to Dunedin for treatment 3 hours distance. We had a machine set up at home and any problems were dealt with from Dunedin. Initially we didn't have that many visits, maybe once a month, but as time went on it became more frequent and often it was for several days at a time.... I was still working and I couldn't always be there and I was 3 hours driving away. I made a few fast trips to be there at times.

After 14 months on dialysis, my husband received a kidney in 1992. The kidney was great for 10 years. And then it slowly deteriorated and the effects of all the drugs he had to take then started to have an effect and he endured major heart surgery, a heart infection, and ended up a double amputee (he wasn't a diabetic thank goodness) and his kidney gave up and it was back onto dialysis.

At that time, I was working part time and we had rental shed that we leased out, and suddenly getting funding became a mission. We evidently weren't eligible for travel and were not entitled to any help so life was a real challenge at the end. I was due to have major surgery on my neck. I was losing the use of my arms and legs and without surgery I was going to be in a wheelchair!!!! I was going off work for 2 months and couldn't lift etc. and hubby was on dialysis and a double amputee. I lost the plot again at that point. As it turned out he died and was buried about 10 days before my surgery.

Lesley Miller RWNZ member

8. The chances of being selected for donation may also be reduced in rural areas as people may have to travel at very short notice to get to the nearest major hospital. A number of international studies suggest that those living in rural areas, spend longer on waiting lists and have a much lower chance of receiving an organ transplant, than those in urban areas. ¹

My late husband's kidney came from an unknown donor. I remember distinctly the night the specialist rang. It was about 5.40pm at the end of June and we were asked to be in Christchurch at am. We lived in Central Otago so it was about a 5-6 hour drive We owned a business had 2 children still at home, had to have tea and get on the road not knowing when we would be back. It was the year that Canterbury had 2 major snow storms and hubby said he would check if we had chains in the meantime he was wandering around in a daze as to how he could be so lucky. We got to Lake Tekapo and he finally tells me that he couldn't find the chains. Here's hoping we don't meet any snow I thought. We were lucky.

The kidney transplant was successful and after time in Christchurch he was transferred to Dunedin where he had to stay until all his tests were normal. That was a challenge as to where to put a man on his own for a long-term stay and not cost a fortune. Fortunately a friend come up with a suitable solution.

¹ Axelrod DA, Guidinger MK, Finlayson S, et al. Rates of Solid-Organ Wait-listing, Transplantation, and Survival Among Residents of Rural and Urban Areas. *JAMA*. 2008;299(2):202-207. doi:10.1001/jama.2007.50. Nicholas A. Gray, Hannah Dent, and Stephen P. McDonald. (2011). Renal replacement therapy in rural and urban Australia *Nephrol. Dial. Transplant*. first published online October 9, 2011 doi:10.1093/ndt/gfr584

New Zealand needs a fully functional national donor register.

9. RWNZ are very disappointed that this paper dismisses the option of establishing a stand-alone national donor register in favour of making improvements to the current driver licence registration system. We feel strongly that the current system of donor consent is fundamentally flawed and unlikely to be rectified by the suggested improvements in this paper.
10. The value in having a stand-alone national register, is that it would provide a mechanism for all New Zealanders to communicate their wishes to donate, not just those who are holders of drivers licenses. For example, Michael Boyes a young deceased Wellington man, whose organs were used to save the lives of seven strangers this year, did not have a drivers licence. His family's decision to donate his organs was made out of sheer luck that he had communicated his wishes to donate to his sister.
11. in our mind this case also highlights the importance in having family discussions on donation and a system that supports consultation with family, before rather than after tragedy strikes. Under the current system, the deceased's wishes are often overruled by the family who are forced to think about organ donation in what is an incredibly difficult time. Some of our members have had first hand experiences with donating the organs of their loved ones. Their experiences highlight the support needed for families through this process.

On February 26th 1975 my daughter was knocked off her bicycle when returning from High School. She never regained consciousness and on Friday 28th 1975 her life support was turned off. As her parents we gave consent for her kidneys to be transplanted. At Christchurch Hospital this procedure was fairly new and some months later we were visited by the medical staff to ask if there could have been anything they could have done to assist us through the procedure. I hope that more support is done now for those consenting. I do not regret this decision as it helped someone to live longer and enjoy life.

RWNZ Member

Just aware of 2 families who donated everything they could when their children were declared brain dead and how much I admired them for doing that. It does concern me that we can elect to donate organs on our drivers licence but family can overrule that wish. Maybe we need a national register where people's wishes could not be reversed.

RWNZ Member

12. We think a stand-alone national register could be better designed so that it provides opportunities for families to be consulted on donor registrations. For example, it could notify nominated family members of a person's decision to register for donation and provide them with information on the organ donation process. Encouraging these discussions to take place is likely to greatly reduce the high number of family objections that currently occur in New Zealand.
13. A national register could also be designed so that it:
 - Provides donors with the information needed to satisfy the medical view of informed consent. As discussed in the paper, clinicians are reluctant to treat registration on the drivers license system as informed consent. This paper suggests that better information could be provided when people fill in their licence application. However, this suggestion misses the fundamental point, that it is inappropriate to ask people to make such an important decision by ticking a box on a drivers license form. The benefit of a national

register is that it could be used in health care settings, where a medical professional could directly provide advice and information.

- Is accessible across clinical settings/DHBs nationwide, and is supported by a set of robust national protocols around its clinical use. This could include asking people if they want to donate at the time of registering with a health professional or are admitted to hospital. A set of robust protocols would also support consistency in the way that DHBs respond to the wishes of the deceased to donate, and communicate these wishes to their families.
 - Can be used as a public awareness tool, to provide information on the benefits of organ donation. There is a fundamental lack of public awareness around organ donation in New Zealand. Sadly the benefits of donation is not something that people tend to think about, until they, or a loved one, are in need of a donor.
14. One of the factors the discussion document raises in opposition to a national register is the “significant costs likely to be involved in its establishment”. However, no cost-benefit analysis appears to have been undertaken by the Ministry to support this conclusion. We do not think that the Ministry should be discarding any of the proposals in this paper, until it has embarked on a robust comparison of their relative costs and benefits.

Support a review of the form and function of Organ Donation New Zealand

15. RWNZ support the recommendations by Ernst Young, that Organ Donation New Zealand (‘ODNZ’) should continue to be the national co-ordinating body for organ donation, but that its form and function should be reviewed. We think that the appropriate location for this organisation is either, within the Ministry, or as a stand crown entity. Either way, it should no longer be tied to a specific DHB, and it should be subject to ongoing oversight by the Ministry. This is necessary to ensure that it is meeting and reflects national objectives.
16. In terms of its functions going forward, we think ODNZ should have a clearer mandate to ensure regional equity in the matching and allocation of organs. As already discussed in our submission, overseas studies indicate that there could be disparities in organ recipient rates between different population groups. This includes disparities between rural and urban populations, with rural people being less likely to receive an organ transplant. More analysis could be done on this issue in New Zealand by comparing rates of organ donations in different DHBs to identify any regional disparities. Information from the Death Audit could be used for this purpose.

Proposed improvements to clinical governance framework for organ donation

17. We agree with the proposal to develop a nationally determined clinical governance framework for organ donation. This is necessary to remove inconsistency practice amongst different DHBs and to ensure a standardised process. We think it is likely that some DHBs will need additional funding to support them in meeting the cost of implementing new systems and processes.

Financial support for donor and transplant hospitals

18. We strongly support the proposal to reintroduce a national funding model to reimburse hospitals for the costs incurred in the donation process. The fact that hospitals are currently internalising these costs, may reduce incentives to increase organ donation rates. Smaller regional hospitals, in particular, are likely to face much higher costs than larger centres in arranging to receive or transfer organs. This could be contributing to inequities in access to donor organs.

19. RWNZ thank the Ministry for the opportunity to submit on this Bill. Please do not hesitate to contact me using the contact details below if you would like to discuss our submission further.

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Wendy McGowan, National President. Margaret Pittaway, National Councillor, Health Portfolio

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