



## Gifts of life in short supply

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In common with most westernised countries, New Zealand has developed organ transplant services to a high degree and achieves excellent outcomes. However, it has had less success in meeting the challenge of organ donation and this is now the critical factor limiting transplantation. In this respect, New Zealand and Australian states (with the exception of South Australia) stand out as low achievers in stark contrast to the USA and most European countries, where cadaveric organ donation rates are substantially higher than our own. Spain in particular has more than doubled its donor rate over the last decade, and now consistently reports cadaveric donor rates above 30 per million population per year.

In New Zealand over the last decade, there have been between 34 and 46 (10 – 12 per million population) cadaveric organ donors per year.\* In 2000, 41 cadaveric donors contributed 75 transplantable kidneys, 34 livers (7 used in Australia), 13 hearts, 16 lungs (4 used in Australia), 3 pancreases and other tissues. These donors were exclusively people who were on ventilator support in an intensive care unit and had suffered brain death, usually from trauma or intracranial haemorrhage. Consent to proceed to organ donation had been obtained from the families of the donors, and the enormous contribution that these families have made requires recognition.

Organs for transplantation may also be obtained from living donors in the case of kidneys and (occasionally) livers. In New Zealand, approximately one third of kidneys transplanted come from living donors (31 of 106 in 2000). The donors are most commonly blood relatives (usually parents or siblings) or emotional relatives (spouses or friends), but occasionally there is no relationship between the donor and recipient. The ethics of “altruistic” donation have been debated, but there does not appear to be any substantial argument against this type of practice and, in the view of many health professionals, it should receive greater acceptance. Overall, living donors make a substantial contribution to our transplant programmes at considerable personal cost for which they receive little recognition and no compensation.

The demand for organs for transplantation exceeds supply and the shortage is most marked (in terms of numbers) for kidney transplantation. The number of kidney transplants performed in New Zealand each year has remained relatively static, at between 96 and 112, in the years from 1996 to 2000. This is in the face of an increase in the number of patients awaiting kidney transplantation; that number now stands at well over 300. Furthermore, the number of new patients who require treatment for end-stage renal failure each year is increasing and reached 411 in 2000. Most patients now wait in the region of two or three years before receiving a transplant, unless they are fortunate enough to have a living donor. Waiting is associated with relatively poor health and consumes large quantities of health resources, principally because dialysis is very expensive. Transplantation, on the other hand, substantially improves quality of life, improves survival, and is cheaper.

There are many reasons for the low cadaveric organ donation rate in New Zealand, but experience from Spain, the USA and South Australia suggests that it should be possible to improve our performance by addressing three key factors.

First, we must ensure that intensive care unit staff recognise all potential donors. Many more people die each year in intensive care units from brain injury than become organ donors. When this subject has been studied, it has been clear that some people who suffered brain death were not considered as potential organ donors. Sometimes this is through oversight, sometimes through misunderstanding of what is required to be an organ donor, but probably more frequently because of early withdrawal of treatment before formal brain death testing.

Second, it is imperative that consent for organ donation is sought in an appropriate way in all cases. Organ donation is usually considered under difficult circumstances. The trauma suffered by grieving families and the intensive care unit staff can lead to some reluctance to approach families about organ donation. Often it is felt that to do so may increase the burden placed on the family, but evidence suggests the opposite and that by not being asked families are denied the opportunity of some good resulting from tragedy. It is known that consent rates are influenced both by the timing and method of approach and that staff need specific training on how these difficult circumstances are best handled.

Third, other issues that lead to low rates of consent for organ donation need to be addressed. Enhanced public education on the need for organ donation and the benefits that result is much needed. The recording of donor status on driving licences, often an important “point of contact”, will never achieve significant results in isolation and may have inhibited other initiatives. New Zealand’s focus on donor registration may be one reason resources have not been put into more effective means of promoting organ donation and raising national consciousness of the issues. In New Zealand, for legal, ethical, cultural and pragmatic reasons, the family of potential donors will always be consulted for permission to proceed to removal of organs. It is therefore vital that family members are aware of each other’s wishes through open discussion. Other factors that may reduce consent rates are lack of public understanding about brain death and its implications, and lack of trust in doctors and other health professionals.

Particular attention must be given to Maori and Pacific peoples, who have substantially higher rates of renal failure than do other New Zealanders. This is principally because of a far greater prevalence of diabetes and diabetic nephropathy and is reflected in the patients on dialysis. In 2000, fully one third (34%) were Maori and another one fifth (19%) were Pacific peoples, far in excess of the expected proportions based on the New Zealand population (15% Maori, 4% Pacific peoples). However, only 34% of Maori and Pacific people with renal failure were waiting for a transplant in contrast to 59% of other New Zealanders, and disproportionately fewer actually received a transplant. In 2000, Caucasoids received 76% of renal transplants, but only 12% went to Maori, 4% to Pacific people and 8% to others, mostly Asians. The national organ allocation system introduced in 1999 is fairer than its predecessor, but its focus on tissue matching probably largely explains this discrepancy. The chance of a good tissue match for Maori or Pacific people is low because very few of them become cadaveric donors. In fact, in the 5 years from 1996 to 2000, 94% of 204 donors were Caucasoid and only 3.5% Maori, 1% Pacific people, and 1.5% other

ethnic groups. Opinions on why this is so vary. Some Maori have cultural objections to organ donation, but these may be less widespread than is often supposed. Nevertheless, consent rates among Maori and Pacific people are particularly low and may reflect unfamiliarity with the concept of brain death and its acceptance, mistrust of medical staff, and issues such as the retention of organs and tissues at autopsies. There is also a general lack of public knowledge of the particular transplant needs of Maori and Pacific people.

If New Zealand is to increase its donor rate, specific action is needed. Excellent work is already undertaken by our organ donation coordinators but they are grossly under resourced. Existing efforts are simply not enough and have failed demonstrably. The hallmarks of successful donor programmes elsewhere in the world include: proactive donor detection in intensive care units staffed by specifically-trained and motivated nurses and doctors; systematic audits of all deaths occurring in intensive care; and fostering of a positive or supportive social atmosphere with a coordinated national public focus on transplantation.

What should be done in New Zealand? Immediate action to ensure that all potential donors in intensive care are recognised and considered; formal brain death protocols in all ventilated patients with severe brain damage and fixed dilated pupils; and discussion of all such cases with the national donor coordinators. Development of a National Donor Organisation with a formally-appointed medical director and appropriate budget is urgently needed. This would permit greater support for existing education initiatives for intensive care unit nurses and medical staff (including the Link Nurse Programme, Medical ADAPT (Australasian Donor Awareness Programme) and Nursing ADAPT), and would be a vehicle for quality initiatives such as audits of intensive care deaths. It would make medical advice readily available to donor coordinators and be a force for national public education and the promotion of organ donation issues within the Ministries of Health and Education. Specific education initiatives that might be considered would include introduction of organ donation issues into school curricula, and specific partnerships with Maori and Pacific people to assist in addressing their needs.

\* Figures quoted are taken from Statistics New Zealand and the 2001 annual reports of the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) and the Australia and New Zealand Organ Donation Registry (ANZOD).

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