



Petition 2002/25 of Andy Tookey and 1,169 others

Report of the Health Committee

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Petition 2002/25 of Andy Tookey and 1,169 others

Summary of recommendations

We recommend to the Government that it:

- fund ongoing education for health professionals on organ donation
- fund an appropriate ongoing national public awareness campaign aimed at increasing the organ donor rate
- establish and fund a national organ donation agency responsible for organising, supporting, auditing, and reporting on the national organ donation system
- require the national organ donation agency to coordinate the collection of organs and to train and educate those carrying out the collection
- establish a dedicated national organ donor register to replace the current system linked to the driver licensing system
- review service and resource allocation issues associated with organ donation and transplantation services
- develop a system to encourage active discussion about organ donation between potential donors and their families
- develop nationally consistent protocols for gaining consent from next-of-kin for organ donation.

The Health Committee has considered the petition of Andy Tookey and 1,169 others requesting that the House take action to address the organ donation shortage in New Zealand. The petitioner highlighted four particular concerns with the current system. He noted there is a lack of public education or advertising regarding organ donation; some doctors are not approaching potential donor families; families can override the wishes of the potential donor; and there are problems created by tying the driver licence system to organ donation.

We share the petitioner's concern at the current level of organ donation in New Zealand, and the inadequacies of the current system for recording donor preferences. We explore these issues below.

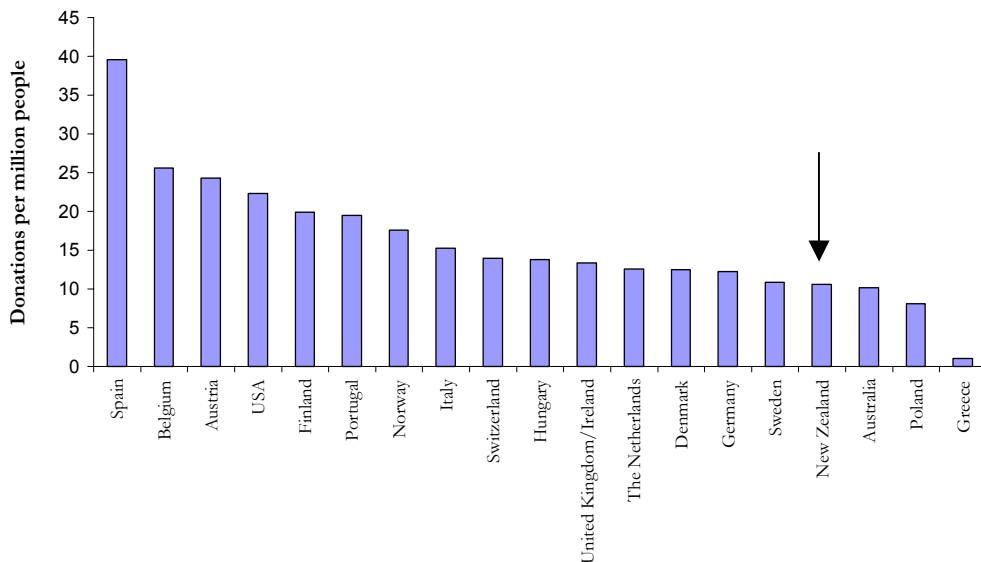
We have sought evidence on the current system for organ donation and considered other international models. We have focused our consideration on donation of organs from brain dead persons, rather than on donation from live donors.

Organ donation in New Zealand

Transplantation began in New Zealand in the 1940s with corneal grafting. The first organ to be transplanted was the kidney in the mid-1960s, and heart valve transplantation also commenced around that time. Bone was first transplanted in the early 1980s and heart transplantation began at Green Lane Hospital, Auckland in 1987. Skin transplantation commenced in 1991, lung transplantation in 1993, and liver and pancreas transplantation in 1998.¹

Since 1993, the New Zealand donor rate has fluctuated between 34 and 46 donors a year. The graph below illustrates comparative international donation rates for the year 2000. For 2002, New Zealand's rate of organ donors for each million population was 9.5, compared with 10.6 in Australia and 32.5 in Spain. As many as 350 New Zealanders are on waiting lists for organ transplantation, mostly for kidneys.

Figure: Organ donation comparison for the year 2000²



The Human Tissue Act 1964 provides for the retrieval and use of organs and tissue solely with the prior consent of the brain dead person.³ However, in practice medical practitioners are unwilling to retrieve organs and tissue without the consent of next-of-kin.

Land Transport Safety Authority collects information on potential donors

The Land Transport Safety Authority (LTSA), as part of the driver licensing process, collects information on those registering their wish to be organ donors. The LTSA database has more than 1.1 million people registered as donors. The LTSA donor information is available to designated health professionals 24 hours a day. However, this

¹ National Transplant Donor Co-ordination Office <http://www.donor.co.nz/background_f_b.html> (last accessed 19 November 2003).

² National Transplant Donor Co-ordination Office <http://www.donor.co.nz/facts_figures_f_b.html> (last accessed 19 November 2003).

³ Appendix B summarises the provisions of the Act in this regard.

information is normally accessed only if a family is uncertain whether to consent to donation and the wishes of the person are not known by the family. The Ministry of Health is not able to access the information.

The organ donor flag on driver licences was first introduced when synthetic paper licences replaced booklet driver licences in 1988. If licence holders ticked the appropriate box on the form, the word 'donor' was printed on their licence and their record on the national register was amended accordingly. At that time, it was considered that this simple system would be sufficient.

The synthetic paper licences issued at that time did not need to be renewed until the end of the month of the holder's 71st birthday. This severely limited the ability to update information on organ donation for most existing licence holders. Over time, the accuracy of the information collected through the driver licensing system would be increasingly out of date, and reliance on this as an accurate reflection of the licence holder's current wishes was risky. This is still true to an extent with the current 10-yearly cycles of licence renewal.

Donation rates linked to intensive care bed availability

One factor affecting the donation rate is the number of intensive care unit beds. New Zealand has 69 intensive care unit beds for each million people, compared with France with 384 per million, the United States of America with 305, Spain with 148 and Australia with 88. Intensive care treatment is needed for potential organ donors, as a person's body needs to be kept on mechanical ventilation after brain death so that blood continues to be pumped to the organs.

Limited intensive care bed availability can reduce organ donation as some potential donors cannot be admitted to intensive care. It can also mean mechanical ventilation is withdrawn early from patients who subsequently suffer brain death.

Organ donation in other countries

Research carried out for the Nana Sue Project, funded by Quality Shoe Marketing, considered international laws on organ donation in some detail.⁴ That report noted that many countries have a system where express consent is needed for the organs of a brain dead person to be removed, as in the New Zealand system. The other common system presumes consent. In such systems, unless individuals have registered an objection to having their organs removed upon their death, they are presumed to have consented to becoming an organ donor. The latter system applies in Spain, which has a much higher donation rate than New Zealand.

⁴ *Organ donation: A Comparative Legal Analysis and Options for Change in New Zealand* Paper prepared for Nana Sue Project, Quality Shoe Marketing, Wellington. Funded by an Education Grant from Roche Products. Chen Palmer & Partners, Wellington. September 2003.

Options for improving the donation rate

Both the petitioner and other submitters had many practical suggestions for how the donation rate could be improved. We considered in particular education and training of medical staff, the role of the donor coordination office, and the most appropriate method of donor registration.

Education and training for medical staff

We consider appropriate training of medical staff is a key first step in increasing donation rates. While staff do not need to be specifically trained to be able to offer the option of organ donation to families, ongoing training would ensure that potential donors are identified, families are approached in a sensitive manner, and donors are managed so that the organs are suitable for transplantation.

The ministry notes that one of the roles of the National Transplant Donor Co-ordination Office is to provide education on organ donation for health professionals. In May 2001 the ministry funded the donor office to provide the Medical Australasian Donor Awareness Programme for Transplantation. This is a one-day workshop for medical staff that covers identification of donors, management of donors, offering the option of organ donation, breaking bad news to families, grief, and bereavement.

A similar programme for nursing and other hospital staff has been in place since 1995, funded through sponsorship. This sponsorship has now ceased, and the ministry is considering funding for this programme as part of a wider review of funding for the donor office.

We sought evidence from Dr Stephen Streat, an intensivist working in the Department of Critical Care Medicine at Auckland Hospital, to provide us with the perspective of a practitioner working with potential donors and their families. Dr Streat noted that any increase in organ donation rates would require a national system to be put in place that ensured all intensive care unit senior medical staff were appropriately trained in organ donation and worked as part of a collegial network of organ donation professionals. He also suggested that only a minority of the doctors performing these duties have undertaken the training so far.

Recommendation

1. We recommend to the Government that it fund ongoing education for health professionals on organ donation.

Role of the donor coordination office

The transplant donor coordination service began in 1987 with the commencement of heart transplantation at Green Lane Hospital. Today, the National Transplant Donor Co-ordination Office facilitates the retrieval of hearts, livers, kidneys, lungs, pancreata, bone, corneas and heart valves. The donor office is funded through the Auckland District Health Board and does not have direct reporting lines to the Ministry of Health.

The office coordinates the retrieval of organs and tissues from donors in New Zealand for transplant units in New Zealand and Australia and for tissue banks in New Zealand. Donor

coordinators provide information and ongoing support for donor families, offer education for health professionals and the public, and report on transplant activities.

The office does not currently have the resources to develop a high level of public awareness. Apart from its website, the office has distributed pamphlets about organ donation to some medical practices. We are not aware of any other national publicity initiatives organised by the office. Some information regarding organ donation is included in information packs sent to driver licence holders prior to their licence expiring, but this information is paid for by a private charitable trust.

We consider this public awareness aspect of the office need to be further developed. A strategy needs to be developed to encourage families to discuss organ donation, so that if they are offered the option of organ donation, they have already had an opportunity to consider the issue. The ministry suggests that education and training for health professionals is a greater priority than public awareness. We agree that health professionals must be adequately trained, but consider that public awareness must sit alongside this.

Dr Streat suggests that there should be a national organ donation agency with a mandate to organise, support, audit, and report on the national organ donation system. People with the necessary interpersonal and clinical skills should be identified in every intensive care unit. These people should be developed so that families of potential donors receive good information, adequate time and support in their decision-making process, and an opportunity to discuss their concerns and have their questions answered. We agree that this would be an appropriate role for a national service. We would also like to see the service coordinating the collection of organs, and ensuring appropriate education and training of staff collecting organs.

We note that the donor coordination office has proposed renaming itself 'Organ Donation New Zealand' and has established an advisory board of health professionals involved in organ donation. The ministry has established an advisory group comprising district health board chief executives and senior managers from the ministry to look at national service configuration, including whether the coordination office stays with the Auckland District Health Board or some other arrangement is put in place.

Recommendations

2. We recommend to the Government that it fund an appropriate ongoing national public awareness campaign aimed at increasing the organ donor rate.
3. We recommend to the Government that it establish and fund a national organ donation agency responsible for organising, supporting, auditing, and reporting on the national organ donation system.
4. We recommend to the Government that the national organ donation agency to coordinate the collection of organs and to train and educate those carrying out the collection.

Appropriate donor registration

We suggest that the system for recording wishes regarding organ donation should change. We consider there are too many difficulties with the current method of using the driver licensing system. We would like to see a separate system that provides for a central register that can be readily updated and is sufficiently flexible to record specific wishes regarding organ use after death, both for donation and research.

Many problems with the current registration system were drawn to our attention. The Ministry of Health told us that the LTSA driver licence database does not meet the requirements to be recognised as a health computer system under the Human Tissue Act. It also does not meet accepted requirements for obtaining informed consent regarding the donation of organs. As a result, the ministry considers there is no legal basis for any reliance placed on the database to provide an indication of the advance intention of individuals to consent to organ donation.

The system is also inflexible, as potential donors cannot specify which organs they are prepared to donate. This can be a disincentive to ticking the box. The driver licence process does not provide an incentive to discuss donation issues with family. Many who tick the box are not aware that their family can override their wishes regarding donation — something that is more likely to happen if families have not discussed the issue. There is a general lack of information provision at the time of applying for a licence, including information about organ donation in general.

We would like to see further consideration given to a dedicated organ donor register. We are aware that some overseas registers have low population coverage rates. Nevertheless, we consider the development of a dedicated organ donor register would be essential in allowing a national donor coordination service to carry out its role effectively.

The ministry is currently reviewing the Human Tissue Act. This review will consider the factors influencing the availability of organs and tissue with a view to developing policy options for a future regulatory framework in this area. However, the review will not address service or resource allocation issues associated with organ donation and transplantation services. We would like to see this review expanded to take on the issues raised in this report.

Recommendations

5. We recommend to the Government that it establish a dedicated national organ donor register to replace the current system linked to the driver licensing system.
6. We recommend to the Government that it review service and resource allocation issues associated with organ donation and transplantation services.

Consent for organ donation

It is clear from the evidence we received that most New Zealanders are not aware that the wishes of their next-of-kin are likely to take precedence over their own wishes. While we agree that families should be involved in the decision-making process, we consider greater weight should be given to the wishes of the potential donor.

We suggest a system be developed to encourage active discussion between potential donors and their families. Any registration system needs to be able to capture information about whether family consent has been obtained, and could prompt potential donors to discuss their wishes with their family.

We considered whether the organ donation system should move from the current system of expressed consent to presumed consent. We note that any such change could only be successful if the population supported it. We do not consider such a change would succeed at this time. However, it is a policy option that should be reconsidered in the future, once public awareness has improved.

Recommendations

7. We recommend to the Government that it develop a system to encourage active discussion about organ donation between potential donors and their families.
8. We recommend to the Government that it develop nationally consistent protocols for gaining consent from next-of-kin for organ donation.

Conclusion

New Zealand currently has one of the lowest organ donation rates in the Western world, and that rate needs to be improved. Demand for transplantable organs is always likely to outstrip supply. Our aging population is likely to increase the demand for transplantable organs at the same time as it creates a reduction in the availability of ideal organs for transplantation. In addition, New Zealand's rate of early-onset type 2 diabetes and subsequent renal failure mean that the gap between demand and supply of donor kidneys is likely to increase.

We support efforts to increase the organ donation rate in New Zealand. The best way to do this is by creating an environment that facilitates donation. Many factors affect the donation rate, including the availability of intensive care beds. We are aware that any change in donation rates will occur gradually, but work started now to increase public awareness and get families talking should impact positively on donation rates in the future.

Appendix A

Committee procedure

The petition was presented by Dr Wayne Mapp and referred to the committee on 5 November 2002. We requested, received and heard submissions from the Ministry of Health, the petitioner, and an intensive medicine specialist. We also received and heard evidence from the Nana Sue Project, funded by Quality Shoe Marketing. We heard evidence in Auckland and Wellington. We met between 11 December 2002 and 25 November 2003 to consider the petition. Hearing evidence took 2 hours and we spent a further 57 minutes in consideration.

Committee members

Steve Chadwick (Chairperson)

Dave Hereora

Dr Paul Hutchison

Sue Kedgley

Nanaia Mahuta

Pita Paraone

Mark Peck

Heather Roy

Dr Lynda Scott

Judy Turner

Dianne Yates

On 30 July 2003, Moana Mackey replaced Ann Hartley as a permanent member of the committee.

On 8 October 2003, HV Ross Robertson replaced Moana Mackey as a permanent member of the committee.

On 5 November 2003, Mark Peck replaced HV Ross Robertson as a permanent member of the committee.

On 5 November 2003, Dr Paul Hutchison replaced Judith Collins as a permanent member of the committee.

Appendix B

Human Tissue Act 1964

The Human Tissue Act provides for the collection and use of a donated body or any specified body part for therapeutic purposes or for purposes of medical education or research. Where a person has requested that his or her body or specified body parts be used for therapeutic, medical research, or education purposes, the person lawfully in possession of the body may authorise such use provided that person has no reason to believe that the request was subsequently withdrawn.

Where a person has not explicitly expressed an opinion regarding donation of organs, health professionals may authorise the removal of any part from the body for use if, having made reasonable inquiries, they have no reason to believe:

- that the brain dead person has expressed an objection to such use of his or her body after death or
- that the surviving spouse, de facto partner, or any surviving relative of the brain dead person has no objection to such a donation.