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Starting the conversation about organ donation

A resource for physicians and paediatricians

in New Zealand

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Contents

Purpose and background.....	2
Organ donation and transplantation in New Zealand	2
Organ and tissue donation	3
Advance Care Planning	3
Early referral to Organ Donation New Zealand.....	4
The role of physicians and paediatricians.....	5
References	6

Starting the conversation about organ donation: A resource for physicians and paediatricians in New Zealand

Purpose and background

As the population ages, the New Zealand health system will need to adapt to provide sustainable and effective management to cope with increases in older patients, chronic diseases, comorbidities, and terminal illnesses to deliver health services and support.

Organ donation provides hope for people with chronic and/or end-stage disease to improve their quality of life. Organ and tissue donations aid patients with a broad spectrum of chronic and acute conditions, including renal and liver diseases, heart failure, rheumatic fever, and respiratory illnesses such as pulmonary hypertension. Donations can come from live donors (particularly in the cases of kidney and liver transplants), or from a deceased person where individual and familial/next of kin consent is given.

Organ donation and transplantation in New Zealand

Rates of organ and tissue donation after death in New Zealand have been described as 'low', by comparison with other countries^{1 2}. In 2015, the Ministry of Health began a review into organ and tissue donation in New Zealand. The review identified local initiatives to increase deceased organ donation and transplantation in New Zealand; considers features of overseas models, and notes New Zealand-specific issues that may impact on decisions to donate.

Following that review, in June 2017 the New Zealand government launched The Deceased Organ Donation and Transplantation National Strategy. "The strategy's priorities include to:

- further increase public awareness of organ donation
- make it easier for people to register, update and share their wish to donate with family and clinicians
- increase the hospital-based capacity for deceased organ donation to take place
- empower intensive care staff to discuss the organ donation process
- establish a national agency to lead the implementation of the strategy, and have a clear mandate to increase our rates deceased organ donation and transplantation."³

It is important that living donors and recipients are informed about their rights to financial or other assistance available to them to ensure that decisions are not compromised for economic reasons. The New Zealand Government provides financial assistance to people who donate a kidney or liver tissue for live transplant. The *Compensation for Live Donors Act 2016*, which received Royal Assent on 5 December 2016 and comes into force no later than 5 December 2017, gives qualifying donors an entitlement to cost-neutral compensation for loss of earnings from employment while they recuperate from surgery, for a period of up to 12 weeks. The Act also provides for discretionary earnings compensation in some circumstances relating to loss of earnings in the lead-up to donor surgery³.

Organ and tissue donation

For people with chronic and end-stage disease, the benefits of organ donation and transplantation are immeasurable, and the value is in their improved quality and length of life.

Patients in end-stage renal disease (ESRD) may receive haemodialysis for hours at a time, several days each week: a procedure resulting in significant compromises to the patient's sense of wellbeing and quality of life. Patients who undergo transplant (either deceased or live donation), show marked improvements when compared to those remaining on haemodialysis. Rates of mortality in ESRD have significantly reduced through organ donation and transplantation^{4 5 6}.

Evidence shows people of all ages are able to donate tissue, including those with chronic illnesses. The specifics of an individual's medical and sociocultural history may influence an eventual organ donation or transplantation opportunity, but there are very few conditions which prevent consenting individuals to donate their tissue^{7 8}. The range of donor tissue required/in demand is constantly changing and includes corneas, bone marrow and skin, with the latter used for skin grafts for victims with severe burns or trauma. Donated skin can be stored for up to one year, and once grafted promotes healing, substantially reducing infection and loss of fluid for patients^{9 10}.

Advance Care Planning

Physicians working in secondary and tertiary hospitals are supported by the RACP to use Advance Care Planning (ACP) as a tool for discussing end-of-life matters such as organ donation. ACP helps ensure that a patient's beliefs, values and preferences are respected for future medical treatment, in order to guide future care in the event that the person is unable to make decisions or communicate¹¹.

The ACP tool enables physicians, patients and their whānau to begin a conversation about difficult decisions that need to be treated sensitively, and can reduce stress and anxiety for patients. The results of these discussions should be recorded on an integrated patient management system where possible, to enable clinical access and reduce patient and whānau distress in having repeated conversations. An ACP may evolve over several conversations and discussions, but always involves the patient, their whānau and health care professionals to achieve patient-centred decisions^{11 12}.

Conversations on the potential for organ and tissue donation in the context of ACP offer physicians a structured process to begin a discussion about donation with patients and whānau. In this context it is essential for patients, whānau and the physicians advising them to have an informed conversation and a sound understanding of the processes involved.

Early referral to Organ Donation New Zealand

Physicians and paediatricians are encouraged to collaborate with their ICU colleagues in order to identify patients for referral. In these cases, early referral is vital to ensure that all donation procedures and processes are followed, that a donor patient's whānau are offered the option of donation, and have access to all the information they require to make an informed and supported decision.

Hospital settings have access to medical specialists who are available to work and liaise with local physicians and the whānau involved.

Early referral can begin when either:

A ventilated patient is in a coma with severe brain damage that is likely to be fatal

Where death is highly likely, or the endotracheal tube is ready to be withdrawn (patients with no motor responses; fixed dilated pupils; have ceased breathing; have lost some/all of their brain stem function)¹³.

Diagnostic processes

The diagnosis of brain death or cardiac/circulatory death must conform with the Australia and New Zealand Intensive Care Society's Statement on Death and Organ Donation to determine death prior to donation¹⁴.

Recommendation for determination of brain death

Determination of brain death requires that there is unresponsive coma, the absence of brain-stem reflexes and the absence of respiratory centre function, in the clinical setting in which these findings are irreversible. In particular, there must be definite clinical or neuro-imaging evidence of acute brain pathology (e.g. traumatic brain injury, intracranial haemorrhage, hypoxic encephalopathy) consistent with the irreversible loss of neurological function.

A minimum four-hour period of observation in tandem with a set of preconditions and clinical testing, which requires two physicians' signatures to arrive at the diagnosis of brain death¹⁴.

Recommendation for determination of cardiac death

The following criteria is required for a determination of cardiac death: immobility; apnoea; absent tissue perfusion, and the absence of circulation as evidenced by absent arterial pulsatility for a minimum of two minutes, as measured by the pulse, or preferably by monitoring the intra-arterial cranial pressure¹⁴.

The role of physicians and paediatricians

All physicians and paediatricians have a role in supporting organ donation.

Physicians and paediatricians are encouraged to familiarise themselves with their local LINK Team and donation coordination system. The LINK team provide the connections between donating hospitals and Organ Donation New Zealand's donor coordinators. LINK teams are comprised of an ICU nurse, ICU doctor (Intensivist) and an operating theatre nurse, and are the local leaders, experts and liaison persons for organ and tissue donation in all donor hospitals in New Zealand.

Physicians are encouraged to consult with a donor coordinator or hospital LINK Team to ensure age, illness and malignancy do not discount the ability for an individual to donate. Donor coordinators provide a valuable connection between the treating physician, the patient and their family/whanau. They also provide information about the conditions that might prove contraindicative for donation.

Physicians and paediatricians can also improve their knowledge on care at end of life and organ donation and transplantation, using a range of resources.

Resources	
The Royal Australasian College of Physicians	Improving care at the end of life: Our roles and responsibilities (2016)
The Australian and NZ Intensive Care Society	Statement on Death and Organ Donation
Organ Donation New Zealand	Best Practice Guidelines for ICUs are available as a smartphone application, downloadable from the iTunes Store or Google Play
	Australasian Donor Awareness Program Training (Medical ADAPT)
	Study days and health professional education sessions, which provide information about the process of organ and tissue donation
Ministry of Health	Te Ara Whakapiri: Principles and Guidance for the Last Days of Life
Ministry of Health	Increasing Deceased Organ Donation and Transplantation: A National Strategy (2017)
Mauri Ora Associates	Māori and Pacific attitudes towards transplantation: professional perspectives (2009)
Webb R and Shaw R	Whānau, whakapapa and identity in experiences of organ donation and transplantation

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