

Submission number: 028
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Date received: 15 August 2008

Submission to

Select Committee on Review of Organ & Tissue Donation QLD

Dear Karen Struthers

Appreciated meeting & talking with you the other month in Hervey bay about organ donation in the Fraser Coast area.

Here are my thoughts on the Issues paper

Section 2

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I realise that this comes from the Federal Reform Package 1 July 08, my concern with this package for us is will this flow on to the rural areas where beds and staff in ICU are at a premium. Without adequate funded & staffed beds in an ICU our brain injured pts are often triaged not to be an ICU admission, (I am know this happens in the Tertiary hospitals as well, their beds are just as scant as ours.). The package talks about funding for ICU specialist Medical staff but seems to forget that without adequate funding for specialist trained ICU nurses this means little as you can only place a pt in a bed if you have enough specialist trained nursing staff to look after the pt (enough physical beds and trained medical staff in reality are not the deciding factor in how many pts an ICU can admit, the RBH ICU is a classical example of this enough physical bed space but not enough nurses to look after the pts if they where admitted in to those beds).

section 3

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The present system of opt in is for the Australian population & the way we look at issues is he best at the present time. There needs to be an introduction of an improved method of providing Informed consent to the population if the present system continues of a consent register not just an intent register. This could be via more media/advertising on O&T donation (as at the moment there is basically nothing if you are honest with our selves, as coordinators we do public awareness each year in February at the time of AODAW plus our community & schools talks, but both governments do realistically nothing.) Informed consent also could happen via the populations GP's who could be forced by legislation (not just another payment incentive to participate) to educate to their pts on donation.

Consent to O&T donation could also be part of the system when people are asked to enrol to vote, this is mandatory thus the population could be asked for their intention at this time. This would cover new enrolees plus people as they move.

Should families still be asked - yes, as how do we know if people have changed their mind losing one set of organs is still better than all the bad publicity that could happen and we loose more yes answers later. As the register is supposed to be a consent via informed consent but

the informed consent is only via what people read and not necessarily what they understand, the family still should be asked to insure of informed consent and correct legal consent, someone still has to sign that consent form, unless there is a system of retrieving the original/copy of the consent form from the AOD Register.

The register should continually be used as is now and that is to help the family decide how to decide to consent or nor consent. The Netherlands system as described on page 13 is always a viable option and offers those that are unable to make up their mind at the time of registration on the AODR an option for them to still register but allow their family to decide thus releasing them from making that decision right now which they might nor be able to psychologically make at this point in time.

The idea of the introduction of an OPT OUT or PRESUMED consent system my thoughts - **WILL IT HONESTLY CHANGE ANYTHING, NO.** Australia is different to European countries in the physical landscape of our vast landscape & sparse population centres, our transport laws and system, types of trauma and medical admissions in to our hospitals and our population's views on life, ethics and morals. The comments on page 15 about Spain and when the rates increased is support to the failure of the Opt Out system alone to improve donation rates. Shifting to a Opt Out system is not suddenly going to improve donation rates, you first need the pts in a funded ICU bed with funded trained ICU nurses and medical staff mandated and protected by legislation to consider organ donation as a normal treatment decision not just an option to be decided at their wim or feelings at the time, then we will start to see an increase in rates (pts have to make it to ICU before you can consider them.)

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Presumed consent should not be considered unless Australia as a whole is considering it as a viable option, then these should be discussed as a nation not at a state level. Queensland should not be different in its system of consent.

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I feel the current system of consent is appropriate, with the following suggestion.

Nursing and medical staff mandated to consider organ donation and all potential brain dead pts refereed to a central organisation with dedicated specialists to make the decision if the pt should be considered for donation, this will help to remove some of the problem of ICU medical staff deciding against organ donation due to their personal views. This can be audited via hospital death reviews/audits completed by non-biased staff, ie Donor Coords.

Section 4

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Actions to high on the list improve donation in Queensland unfortunately all evolve around the money issue, but if we think of savings made by donation in the long term and the lives changed then the cost seems much more acceptable and affordable.

Some of the major changes needed are:

The lack of ICU beds throughout the whole of Qld, no ICU bed means no potential donor in the first place. Increased ICU bed numbers regional and tertiary.

The lack of trained ICU specialist medical staff, some this relates to strangle hold that the specialist medical colleges/societies (ie ANZICS, AMA etc) have on the number of training places available. Increased trained intensivists.

The lack of trained specialist ICU nurses available, this relates to the lack of incentive for people to go in to nursing and the lack of incentive for nurses to take on the increased responsibility of ICU without any recognition for it. Increased trained ICU nurses who are appropriately compensated and recognised for their skills and responsibility.

Mandatory education of medical and nursing staff on organ donation (ie ADAPT)

Mandated referral system developed of all brain injured potential donor pts. (see above)

Incentive payment to hospitals for all appropriate pts brain death tested (similar to dysphagia screen incentive)

Increased hours for Regional Donor Coordinators

Increased federal/state government supported media advertising on organ donation throughout the year not just what the Donor Coords can arrange in February each year, which often depends on whether the media sees it as beneficially to their sales at that time.

If any incentives are offered to donor families (living or dead) they should be to ensure that the relatives are not out of pocket/disadvantaged by having to travel or provide accommodation while their loved ones organs are being retrieved.

Ian Rogers