

District Nursing Association (Established 1904)

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Submission No 26

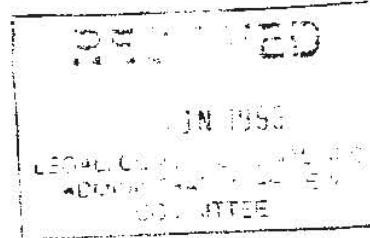
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**St Luke's
Nursing Service**

• Caring Beyond Expectation •

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10 June 1999

Ms Kerryn Newton
Research Director
Legal, Constitutional and Administrative Review Committee

Dear Ms Newton,

Please find attached a copy of a submission for consideration by the committee. The comments and opinions contained in the submission are based on the experience of St Luke's Nursing Service staff who have provided care to numerous transplant recipients and their families. Palliative care is our core business and therefore is a significant theme of the submission.

Please advise if you require any further information we would be most willing to provide further illustrations of our experience. Thank you for the opportunity to participate in these important discussions.

Yours sincerely,

Cheryl Herbert
Chief Executive Officer
St Luke Nursing Service.



Submission

To: The Legal Constitutional and Administrative Review Committee

From: St Luke's Nursing Service

Re: The Transplantation and Anatomy Bill 1998 proposed amendment

Introduction

St Luke's Nursing Service has provided domiciliary nursing services to the people of Queensland since 1904. The service has now grown to 13 branches across Queensland.

The service works collaboratively with hospitals, general practitioners and other community health care services to provide community based care and St Luke's would like to take this opportunity to commend the work of many of the clinicians who work in the challenging field of organ transplantation.

Our clientele have an extensive range of health problems and includes those who have been transplant recipients and their carers. Therefore our service has intimate insight regarding the positive and negative outcomes of transplant technology. Palliative care is one of the major services offered to the community by St Luke's. People who have not been able to access a transplant or who have had unsuccessful transplants are among those who access our palliative care service. The opportunity to contribute to the debate on this amendment is both relevant and timely.

Service Provision

Our experience with transplant patients suggests that persons who have received organ transplants are an extremely diverse group in terms of their levels of social support, compliance with treatment, age and ethnicity. This diversity may contribute to varying levels of success among individual recipients. Consequently the provision of transplant services is a very complex issue. We have a social responsibility to ensure that people are treated ethically and informed of the potential costs associated with transplantation as well as the benefits.

Increased supply of organs alone will not necessarily lead to improved, ethical and balanced decision making regarding the use of transplant technology. There is a need for more awareness of the actual and potential costs to the individual, their family and the wider community. The implications of increasing the number of transplants are: increased health costs; pharmaceuticals; community follow up; potential for complications and the development of other illnesses secondary to other immunosuppression. Indirectly, escalating costs of transplants will require more resources and may decrease available resources for other important areas such as palliative care.

Palliative care needs to be a priority especially for people with unsuccessful transplants who are at present invisible. From this perspective, there needs to be as much emphasis on the provision of quality palliative care to those who are dying as a result of unsuccessful transplants as increasing resources for those who are waiting for transplants.

Some organ transplants are supported by extensive research and development and have become part of mainstream clinical practice (e.g. renal transplants). However, there are gaps in the research of particular areas such as the experience of transplant recipients, their quality of life and ongoing social and health related costs post transplant. Other newer transplant technologies have considerably more research deficits.

Comments on the wording of the amendment

The legalistic language makes interpretation of the amendment somewhat difficult. It seems that clause 3 subsection 3 of the amendment allows for little change to the status quo. That is people who are relying on the license as a legal consent still have to make a judgement about whether the consent has been withdrawn. How would a clinician make this judgement? What issues would lead to the withdrawal of consent? It is most likely that they would involve the family in the decision making. The changes to the legislation should decrease the burden of decision making on the family.

The dilemma is that rarely if ever do people discuss these sensitive issues with family members and seldom is there a clear understanding of the person's wishes. The family would still be confronted with the difficult decision and may supercede the potential donors desires or consent. Involving the family and/or carers in decisions at an early stage is much more preferable to expecting a recently grieving family to make decisions about organ donation.

As health care providers it would be irresponsible to allow the amendment to be passed without wider discussion in the community to explore the consequences and positive aspects of organ transplants. More onus on the medical community to raise the issue of organ donation with families in a sensitive and timely manner is required. The government needs to facilitate this discussion.

Comments on the Private Member's second reading speech

The speech attached to the invitation for written submissions contained several statements that presented a somewhat imbalanced view of transplant services. The low rate of organ donation in Australia for example, may not be completely negative and there may be sound social and cultural reasons that families choose not to consent to donation of their loved ones' organs. The overwhelmingly positive view about the way that organ donation saves thousands of lives and increases quality of life was also not a balanced reflection. Many recipients of organ transplants suffer serious complications and secondary health problems severely compromising their quality of life. There are varying levels of success of transplant surgery and the example of the cadaver arm transplant is not a credible or reasonable benchmark for success. The catch phrase "we have the technology" could be followed by a cautionary "but should we use it?" Also the comments regarding the media portrayal of the experience of organ transplantation raises the issue of relatives having no forum to voice their dissatisfaction when they feel that they have been treated badly.

Other Issues

Several related and important issues of concern that have not been raised include: the changing expectations of the community and peoples acceptance of death. Many of our clients choose to die in their homes surrounded by loved ones and in a familiar environment.

There is a significant imbalance in the allocation of resources biased towards highly technical, costly clinical interventions. These also enjoy a high profile in the media and attract a large portion of the health care dollar. However, community services remain as supplicants to hospitals who control most of the resources. There is a need to redistribute resource allocation to the community to provide direct care to those who benefit from the transplant technology and for those for whom the technology has been unsuccessful.

The Power of Attorney Act 1998 contains the Advanced Health Directives. These could be used to obtain a more comprehensive form of consent including discussions with medical practitioners. Currently this is not included in the Advanced Health Directive.

Recommendations

There is a need for a model of decision making that includes a component for advocacy for families and a focus on those who have had unsuccessful transplants.

Public debates are needed on organ transplants (recipient and donor issues) and palliative care focussing on costs, social capital, community development and issues of ethnicity and cultural sensitivity. These debates should involve recipients, their families and donor families.

A forum for bereaved families to air their negative experiences. The involvement of the Health Rights Commission may be appropriate in this regard.

A Legislative amendment to enable utilization of the Advanced Health Directives to obtain more comprehensive form of consent.

More resources for research in the social and public health issues related to transplantation.