

## **PRIVATE SUBMISSION**

### **TO PARLIAMENTARY SELECT COMMITTEE REVIEW OF ORGAN AND TISSUE DONATION**

**By CARL MYHILL PEDERSEN**

I was first diagnosed with kidney disease in early 1984. The symptoms were detected in a regular medical check-up to which all servicemen and women were subject. Through proper management (medical, dietary and exercise) I was able to lead an active and meaningful life for another 20 years before reaching end stage renal failure and being placed on dialysis. Even when on dialysis I was able to retain a meaningful role at work but I could not continue to live a full and active social life, due to the time required on dialysis and the general deterioration of my health. However, in late 2004, I was fortunate to receive a kidney transplant. Though the 14 months following my transplant were full of medical difficulties, I managed to survive this period with excellent professional management, and once again I am able to live a full and meaningful life.

I am a member of the Kidney Support Network (KSN) of Queensland and very much appreciate the opportunity accorded our CEO, Ms Kay Schafer, and myself to attend your public hearing on Friday 5 September 2008 as witnesses. However, I was unable to present some recommendations at that hearing, and now appreciate the opportunity to provide these to you as a personal submission.

#### **1. Reducing the need for kidney transplantation through better management of patients with kidney disease.**

This process would involve:

- promoting healthy lifestyles for patients at risk of kidney disease.
- early detection by GPs.
- better management of people detected with kidney disease (medical and lifestyle).

I was able to continue a full and meaningful life for 20 years after the detection of kidney disease.

#### **2. Acknowledge the key role of GPs**

GPs must be further educated in both kidney disease and organ transplantation because they are:

- at the vanguard of early detection and management of the disease that potentially slow the decline to end stage renal failure

- often very influential in a person's decision whether or not to donate their organs and tissues. At a number of public presentations I have provided to community groups, audience members have been poorly advised by their GP as to their suitability for organ and tissue donation.

### **3. Improving the registration process for organ donation**

I believe that the current process could be significantly enhanced by:

- adding a next-of-kin sign-off to the current form. This need not be mandatory but would, I believe, promote family discussion at the time of making a decision to donate. This knowledge could greatly assist organ donor coordinators when approaching a potential donor's family.
- making registration forms more readily available and accessible eg. At GPs receptions, Queensland Transport Customer Centres, Local Government Customer Centres, inserted with motor vehicle registration and driver's licence renewals, as well as providing on-line access with suitable personal identification processes.

### **4. Promoting live kidney donation**

This, I believe, will become a major source of donated kidneys in the future. However, it must be understood that live donors, especially those from rural and regional areas and those who have small businesses and farms, can face significant disadvantage by being off-line for a period of at least one month. I believe that a special case can be made for such donors for better support under the PTSS, given the above disadvantages and the significant savings to the health system through kidney transplantation. Recent figures indicate that the return-on-investment of a successful kidney transplant would be less than one year. The lack of professional counseling to assist potential live donors reach the best decision for them is, I believe, also an impediment to the rate of live kidney donation.

#### **Improve the long term success of kidney transplants**

Though the long term success of a kidney transplant is mainly dictated by medical conditions, I believe the life of a kidney transplant could be enhanced by:

- Extending a "special case" provision for increased levels of PTSS to those kidney transplant patients and their carers from rural and regional areas, small business owners and farmers. These people often face significant financial and emotional stress whilst away from home for periods of up to 3 months, and conflicts therefore between medical and financial needs.
- Ongoing education and involvement of patients in healthy lifestyle programs covering diet, nutrition and exercise.

- Professional counseling services for patients and carers when medical and emotional needs dictate. Such counseling would enable many patients to work their way through these difficulties rather than “give up the fight” or regress to behaviour that would damage the transplanted kidney.

Carl Pedersen