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This submission is written from a very grateful liver transplant recipient and family. Like many in the community, the subject of organ and tissue donation used to be one I thought about in passing, agreed with in principle, knew very little about, but thought was an amazing development of modern medicine. I never expected it would touch me personally.

All that changed in 2001 when I was diagnosed with a rare autoimmune disease of the liver, for which there was and is no treatment, except ultimately a liver transplant. Even then it was not something I really expected to happen or wanted to happen - it is not easy to come to terms with your life being saved by another's death. Due to the shortage of liver donors, the requirements to be accepted on a waiting list are significant and at that time I was not "sick enough" for this. So I carried on as best I could while my condition took me on a rollercoaster ride for several years. Then suddenly my situation took a major downward spiral and early in 2004 I was admitted for the rigorous assessment programme for eligibility for a liver transplant. At the same time I was also told to "put my affairs in order". While I met the requirements for transplant it was clear that my specialists regarded my situation as "touch and go" as to whether I would last the distance to receive the transplant. Words cannot explain how it feels to be in that situation - nor can they express the gratitude and joy of receiving a liver in a successful transplant or what it means to have hope for the future. Happily I am now into my 5th year post transplant - years which have been an unbelievable gift of time for my wife and I to enjoy life together and share experiences with family and friends.

I provide this abbreviated story as background to remind the committee of the recipient side of the transplant story. In particular to reinforce the fact that no transplants are ever undertaken lightly - it is not an easy path to tread even though it is often the only path. The lead-up process is lengthy, rigorous, and emotionally draining. A successful transplant requires the timely coordination of innumerable elements, and the skill and care of many. The care and responsibility of the donor gift is ongoing, often challenging and demanding and continues for the rest of the recipients' lives.

When I look at statistics for organ donation and transplant recipients I know how fortunate I was. I know how close to the edge I came and for me it really is miraculous all the elements came together, all the "what ifs" turned in my favour and I received a new liver. Of course the key element is that of the donor and for this committee the issue of low donation rates in Queensland.

Given that in Australia the public view is highly in favour of organ donation I believe a way forward should be made towards a presumed consent or 'opt-out' system. This provides a safety net for those strongly against being a donor, but would put a system in place which is in line with community attitudes. However such a move should be preceded and accompanied by extensive information/education campaigns on the whole donor/transplant issue.

Over recent years I have had many discussions about this subject with friends and colleagues. While they are generally in favour of being a donor, most have little understanding of the current problem.

- There is considerable confusion over what is required to become a donor - many say "oh, I've ticked the box on my drivers licence", even though this is no longer valid consent.
- Most have no idea that only 1% of all deaths occur in circumstances that will allow transplant - it is widely unknown that the organs of a donor must continue to have blood pumping through them until they are retrieved immediately before transplant.
- Many think organs can be taken from road accident victims who have died at the scene of a crash and therefore there must be plenty of donors about.
- Some think your organs will be "whipped out" rather than treatment given if you agree to be a donor.
- Most have a television view of brain death where the family are told there is "no hope" and then gathers everyone about to say goodbye, before the ventilator is switched off. This is not the reality in organ donation - "brain death" is a clinical decision made by professionals and once the decision has been made for donation, the retrieval of those organs needs to be carried out as early as possible. However, until all is in place for that to occur, the circulation and respiratory function is maintained and at times for the donor family it seems the donor is still "alive".

The reality of organ donation can be difficult to come to terms with - it is a time of enormous grief and distress and not the time to be making such decisions. I believe that a presumed consent system will relieve this burden for the families of many donors and enable the donor/transplant process be improved to provide the best outcome for all parties. However to work well there needs to be a much greater community awareness of what is involved, together with a much improved and more extensive system of coordination within hospitals. The Spanish model seems to indicate that a presumed consent system will only improve donation rates if it is backed up appropriately by coordination teams.

One point which does not appear to have been specifically considered in relation to organ donation rates in Australia compared with the rest of the world, and which certainly is relevant in Queensland, is the fact of the vastness of our country and the widespread placement of our population. It would seem to me that the system of consent becomes irrelevant where there are no ICU facilities at all, or no appropriately trained donor coordination staff. I note these areas are part of the Federal Government funding initiative announced on 2 July this year and I would

strongly urge the committee to support these initiatives and for the Queensland Government to do all it can to assist in such improvements.

The matter of family/next of kin involvement in the decision making process is difficult and I know from discussions with donor/transplant staff that in practical terms they are reluctant to proceed with donation if the family have concerns - even if the deceased was in favour. I doubt there is an easy solution to this aspect of the issue and it would appear to be problematical no matter what consent system is in place. The improvement/addition of donor coordination services may assist in this area, as would more open discussions of the matter amongst family members. While I do not advocate a hard/strong presumed consent system which may cause unnecessary distress for families and for hospital/coordination staff, I do believe the wishes of the deceased should be paramount and every effort should be made to carry them out.

Even if the committee should decide not to recommend a presumed consent system I believe it is important to open public discussion on the subject. Current levels of community support for organ donation should be used to move the debate forward and the Queensland Government should provide funding to improve public awareness on the matter. The work of Queenslanders Donate is outstanding, but severely hampered by lack of staff/funding. The level of ignorance and misinformation in the community about organ donation should not be underestimated. Even within the medical profession there are gaps of knowledge and understanding on the subject and this needs to be addressed immediately in a thorough and systematic way.

While time consuming and costly I believe a personal approach to improving awareness is the key - through educators at schools, community groups and within industry, as well as information booths at shopping centres etc. I believe donor rates will improve if the public has the opportunity to ask questions and get answers, to listen to personal stories and to be assured of the safeguards in place within hospitals. Organ donation is an emotional subject because it deals with death in sudden and unexpected circumstances. But of course the other side of that coin is the good that can be achieved from organ donation. This message is not one easily conveyed in a brochure or a community announcement. It is very personal. Anyone who has attended the annual Service of Thanksgiving for Organ and Tissue Donors will understand that organ donation is overwhelmingly emotional, but is also a positive for donor families as well as for recipients.

Despite a general lack of understanding about many of the issues involved, I have found there to be a great amount of community goodwill and support for organ and tissue donation, and for the way it can and does change the lives of recipients. I believe the community is ready for this discussion, but would remind the committee that statistics are meaningless without an understanding of the emotions involved, or why people are making the decisions they do. Any change needs to come from within the community. I do not believe it will succeed if it is imposed from above.

I wish you well and thank you all for your time and effort in being a part of this committee.