

# Organ and Tissue Donation (Deemed Consent) Bill

26/7/21

Dear Sirs,

Many thanks for your email asking for my views on the above bill.

## **My Background.**

I signed up to become an organ donor when I was 14 years of age principally for moral reasons as my organs could be used to save lives.

Years later our family were in the unfortunate situation where our daughter's kidney failed and she needed a kidney transplant. I was able to observe what it is like on the journey where you need a transplant and all the processes involved. Currently I am chair of the charity Northern Ireland Kidney Research Fund but in this article I will be expressing my own personal views.

Transplantation is unique in that it depends firstly on the goodness of a human being to enable it to happen. Thus the really important element in this is raising public awareness about how necessary this 'Gift of Life' really is.

Anything such as the new deemed consent bill is welcomed as this highlights the need for the necessity of more organ donors and thus saving and improving quality of life.

As Wales, Scotland and England have adopted the 'opt out' system for organ donation and the encouraging figures released from Wales I feel that NI should follow suit along with a compassionate educational programme established in schools and also with the general public. (Encouragement being the effective language rather than enforcement.) In Spain it is seen as a moral obligation to consent and this is what we need to do here.

I think it is important to highlight the necessity that only 1 in 100 of registered peoples' organs can be used thus the need for everyone to be registered. Also that due to our lifestyle it is predicted that many more people will be needing transplants in the future and unless we increase our consent many more people will die.

The financial effects of the bill seem reasonable considering the cost savings made on every transplant. Eg 10 years ago when my daughter received her kidney transplant it cost approx. £45,000 to keep a patient on dialysis and post transplant this dropped to £5000 Hence as we now transplant 100 + kidney patients per year here it is a huge saving.

Lastly I must emphasise that if this bill goes ahead it must be with the assurance that the infrastructure and specialist clinical staff are available. (I say this because of the anguish in the renal community here of cancellations of transplants during the Covid pandemic and inflexibility and difficulties incurred by the clinicians on being able to treat their patients.) In our role as a charity we raise money for renal research

projects and have funded over 100 research fellows. This benefits the whole community of people living with kidney disease here and world wide. Many of these doctors, nurses and scientists are employed here and we are now proud to say that we have a world leading kidney transplant unit at the BCH. We must support and encourage our great renal team.

I hope this is of help. 'Lets Live Life then Give Life.' If I can be of any help please let me know.

Yours faithfully

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