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**Jo-Anne Dobson MLA**

**Room 307 Parliament Buildings, Ballymiscaw, Stormont  
BELFAST BT4 3XX**

Dear Jo-Anne

**Re: Human Transplantation (Northern Ireland) Bill**

If you remember, earlier this year you kindly arranged for me to discuss some points about this Bill with your advisers. I am interested because of my connection with organ donation and transplantation in N Ireland for many years and also because I wrote an assessment of the Welsh Act for the Modern Law Review earlier this year. If you are interested, the ref is: (2015) 78(2) MLR 324-348. I can let you have a copy if you like. In fact I will enclose it, as it might contain some useful thoughts.

However I was also interested to see that the N Ireland Bill has reached a consultation stage, but with some changes. Some colleagues from the British Transplantation Society and UKDEC have sent me a copy of the draft. As I am not very clear about the way in which the Bill is being brought along, although of course I know that it was yourself who launched it as a Private Members Bill, I am not sure if you have a role in piloting it at present. However, having read the draft, there are some difficulties, which I think I should mention.

1. *Positive affirmation of absence of objection.* I note the important section 4(2), which states that donor consent will only be deemed if a near relation or long-standing friend etc positively affirms that the deceased would not have objected. While I understand the motivation for this, it does take away much of the force of deeming. Since the evidence suggests that relations are only aware in about a quarter of cases that the deceased did not object to donating, this would limit deeming to that number. But, in those cases, it would seem unnecessary to need deeming, since the deceased's lack of objection would then be known and in theory the relations should be in a

position to give consent themselves, as is allowed by the Human Tissue Act 2004.

2. *Express consent by relations who are unable to affirm lack of objection.*

However, as the Bill stands, there seems to be a bar to the relations' ability to give this sort of consent.

This is due to a flaw in the drafting. The drafters seem to have copied some of the terms of the Welsh Act into sections 3 and 4 of the NI Bill (Express and Deemed consent) without realising the difference that section 4(2) makes to the overall position.

In the Welsh Act, section 3, Table 1, there is no need to provide for the situation in which the deceased's position on consent is unknown. In that scenario, it is always going to be 'deemed' consent, unless the relatives etc bring evidence that the deceased did in fact object, in which case, of course, there is *no donation*, so there is no role for an option of express *consent* by relations.

But the NI Bill section 4 (2), by requiring positive affirmation of lack of objection, leaves *undealt-with* the case in which, although the relatives might not be able to make that affirmation, because they don't know, they *might still want to give express consent* to donation, as of course they are at present allowed to do under the Human Tissue Act 2004. However, the Bill, as it stands, would make this impossible, because it doesn't provide for it (and also abolishes the application in Northern Ireland of Section 1 of the Human Tissue Act 2004 as regards appropriate consent to organ donation). Since the position we are discussing (no knowledge of deceased's wishes) is the commonest one in practice, the Bill as it stands would prevent most of the donations which now happen under the Human Tissue Act 2004 - unless the relations were to make false affirmations, which doesn't seem right.

So the Bill needs more work to make it coherent. Provision needs to be made for the situation where the relatives are not able to affirm lack of objection and, in the absence of knowledge about this, still want to donate, as they can at present. Maybe this could be done by including the scenario as one of the cases in Table 1.

But, to be honest, it seems to me that the requirement of positive affirmation of lack of objection tends to weaken the concept of deemed consent and therefore the purpose of the Bill, unless this can be presented differently. It might be more in keeping with the real donation situation, as it occurs in intensive care units, to state in section 4(2) that the deceased is deemed to donate unless evidence is produced that either (a) the deceased or (b) the

relations etc objected. This would mean that, even if the family members don't know the deceased's wishes, they still have an opportunity either to accept or reject the idea of donation. Although this is not *very* different from the present need for express consent, being a very soft presumption, it does keep the idea of deeming in existence as the default option and does not effectively annihilate it, as the positive affirmation does. Also, as we all know, even under the Welsh Act, the relations will always be able to prevent donation if they feel strongly enough about it. So this amendment would have a built-in reality check. As I say in the enclosed article, the Welsh Act is really about Encouragement, not Enforcement.

As in Wales, the best thing about the NI Bill is that it imposes a duty to promote donation, which may lead to better public understanding and cooperation. It might be a good idea to wait and see what will be the effect of the Welsh Act coming into force next month before deciding how to proceed with the NI Bill.

However it goes, thank you very much for all the dedicated work you and your team have put into promoting a sustained increase of organ donation in the province. It is very much appreciated and one good result already may be the greater transplantation rates we have been seeing here in the last couple of years.

V best wishes

James Douglas