

**Response to the Welsh Assembly Health & Social Care Committee
consultation on the draft Human Tissue (Wales) Bill, January 2013**

From the Association for Palliative Medicine of Great Britain and Ireland

We support any ethically sound attempt to see an increase in organ donation and transplantation rates in Wales and the UK as a whole. We would like to comment on some of the current consultation questions.

We doubt that “deemed consent” is a form of consent. We think that it is harmful and wrong to use this term for an opt-out system of organ donation.

The family’s role is not clear enough. There are some ambiguities in the account of what influence they have over decisions and whether this role amounts to exercising a veto over retrieval. Resolving these would help to clarify their role. Families’ experience of decisions around the end of life is pivotal in influencing their bereavement reactions and is a significant public health problem as well as one with specific and direct effects on public confidence in organ transplantation.

On capacity, we think that it needs to be made more clear how and when the judgement of capacity should be made within the requirements of the Mental Capacity Act (2005).

Our principal remaining concern is around donation following circulatory death (DCD). Whereas in donation following brainstem death (DBD) all additional interventions are performed after death (defined by brainstem criteria), DCD can entail having additional interventions in the last hours of life purely to facilitate subsequent retrieval and we have concerns about establishing whether these are in the dying person’s best interests.

When a decision on DCD is taken before withdrawal of life sustaining treatment, the person is alive but usually incapacitated. According to the provisions in this Bill, in the case of DCD decisions on transplantation activities and on interventions in support of those activities would not be covered by “deemed consent” because the person is alive at the time, but could not be based on express consent because of incapacity.

It is normally contrary to a person’s best interests to continue non-therapeutic interventions (interventions which do not benefit the patient) if doing so would cause distress. Intervention in support of DCD can be in a person’s best interests on the basis of her express consent because it allows her wishes to be fulfilled. It may be in his/her best interests on the basis of “deemed consent”. There is a risk, although perhaps small, that the donor’s end of life care is harmed by such interventions. We suggest that in the case of DCD care must be taken not to compromise the care of the dying donor for the sake of what amounts to non-consensual retrieval.