



Department
of Health &
Social Care

Parliamentary Under Secretary of State for Mental Health, Inequalities and Suicide Prevention

From Jackie Doyle-Price MP

*Department of Health and Social Care
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Marie van Der Zyl
President
Board of Deputies of British Jews
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By email only to: president@bod.org.uk

25th October 2018

Dear Marie,

I am happy to provide confirmation on three points relating to the Organ Donation (Deemed Consent) Bill 2017–19, in response to issues raised by the Board of Deputies of British Jews. These points concern the operation of the proposed section 3(6B) of the Human Tissue Act 2004 to be inserted by clause 1(4) of the Bill.

This letter aims to clarify the intended operation of the proposed provisions of the Bill but does not act as a supplement to nor prevail over the provisions of the Bill or the Human Tissue Act 2004.

I confirm that the concept of deemed consent for the purposes of organ and tissue donation that is proposed under section 3(6)(ba) only applies in the absence of a decision by the deceased or their appointed representative to consent or not to consent to organ donation.

Neither the Bill nor the 2004 Act prescribes any specific method for signifying non-consent; I confirm that it is therefore up to each person to choose how she or he wishes to indicate their wishes for the purposes of the Bill. The Bill is not prescriptive about how a decision is to be recorded. I expect practical guidance will be set out in the Human Tissue Authority's Code of Practice (the Code) as it is now. The Code does not limit ways in which consent or non-consent can be recorded, only a Bill could do that.

Subsection (6B) deals with the situation where the deceased is not known to have expressed a view as to consent or non-consent, in which case the family and other persons falling within the definition of qualifying relationship are to be consulted. As I made clear in the Government's response to the consultation, as is currently the case, organs and tissue will not be taken without full consultation with persons in a

qualifying relationship. There will always be a personal discussion with the family and full consideration will be given to the views of a person's loved ones. A person's faith designation, whether identified through the register or through discussion with persons in a qualifying relationship, will continue to be a decisive factor in determining the deceased's views regarding consent. Organ donation staff go to extensive and far-reaching lengths to speak to family members in order to enable organ donations go ahead and they will continue to do so. I confirm that going forward, as now, medical and other regulated healthcare professional staff would take all reasonable steps in the circumstances of the individual case, to discover whether persons in a qualifying relationship were available and whether they wished to provide information for the purposes of the subsection. As is currently the case, where an individual cannot be identified or persons in a qualifying relationship cannot be reached, organs will not be taken from the deceased.

I confirm that the Code of Practice will deal with expressions of non-consent in the same way as it presently deals with expressions of consent.

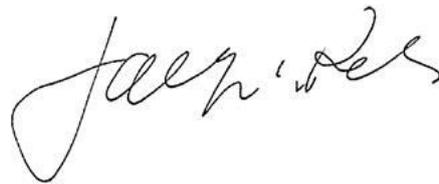
Finally, I confirm that an expression of consent or non-consent for the purposes of the Bill and the 2004 Act could be generic, or it could be conditional or selective. Consent may be limited in a variety of ways. The Bill and the 2004 Act do not prevent an individual from placing limits on their consent via the imposition of conditions, and the Code currently and will continue to set out practical guidance about conditions. The Bill and the 2004 Act recognise that individuals have the autonomous right to selective consent to the use of certain organs and non-consenting to the use of other specified organs.

As confirmed in the Government's response to the consultation, there will be a new option on the Organ Donor Register (ODR) to allow people to state that their decision to donate organs is contingent upon their faith being respected and adhered to in all respects. In order to respect these wishes the deceased's family and, where requested, faith leader should be consulted to determine whether organ donation is a possibility for them and to discuss how donation can proceed whilst ensuring that any religious obligations are observed.

The text on the ODR will say: "I would like NHS staff to speak to my family and anyone else appropriate about how Organ Donation can go ahead in line with my faith or beliefs" and "Record whether you want our specialist nurses to discuss your faith or beliefs when they approach them about organ donation".

I can also confirm that the appropriate agencies, such as NHS Blood and Transplant and the Human Tissue Authority, will engage extensively with faith communities and their representatives in developing codes of practice and guidance, as well as training and education for relevant staff, to explore how best to meet the requirements and concerns of faith communities.

I am happy for you to use this letter when engaging with organisations which are responsible for the organ donation system and to provide re-assurance to the Jewish community.

A handwritten signature in black ink, appearing to read 'Jackie Doyle-Price', written in a cursive style.

JACKIE DOYLE-PRICE