

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Org)9 – South Wales Jewish Representative Council

My name is Stanley Soffa. I am chairman of the South Wales Jewish Representative Council and in submitting this document I am not expressly putting forward the opinion of the Jewish Community in South Wales because organs are donated by individuals and not by organisations, whether or not they are Jewish, but I hope that my comments will be of assistance.

Since the summer of 2012 I have been involved in making submissions on behalf of the Jewish Communities of South Wales and with Rabbi Rose of Cardiff United Synagogue attended a consultation event on the 6th August following which we were invited to a meeting with members of the Medical Directorate in October 2012. Later that month Lisa Gerson of Cardiff United Synagogue and I attended a meeting of the Welsh Assembly's Faith Communities Forum chaired by the First Minister where I put forward the Jewish perspective and in November we, together with Rabbi Rose, had a meeting with Cognition.

I do not intend repeating what was said on these occasions but less it be thought that there has been a change in our approach I would specifically refer to two documents provided to the Medical Directorate, one from the Chief Rabbi and the other from the Board of Deputies. Both pre-date the publication of the Bill but the former shows the approach of those members of the Orthodox community for whom Lord Sacks is currently the Chief Rabbi whilst the latter tries to represent all strands of Judaism in the United Kingdom.

Judaism has always accepted and put great emphasis on our duty to save the life of another and this was reiterated in a statement issued by the current Chief Rabbi in January 2011 when he said

“A living person may donate an organ to save someone else’s life. This is not only permitted but also actively encouraged, provided that in doing so the donor is not putting his own life at significant risk.

With regard to donation after death, in principle Halacha (Jewish Law) permits such donation provided that the organ is required for an immediate transplant and not for research”.

We are therefore encouraging members of the Jewish community to discuss their wishes regarding organ donation and endorse paragraph 43 of the Explanatory Memorandum of 3 December 2012 when it states that “telling close family about wishes relating to organ donation will be one of the key messages of the education campaign which will accompany the new legislation, since uncertainty about what their relative would have wanted is what prevents many families engaging with the organ donation process. This then results in healthy organs being lost to a potential recipient”.

However, where organ donation after death is made in conformity with Jewish practice, the obligation (“*mitzvah*”) to perform an act of “*pikuach nefesh*” (saving a life) rests with the family of the dead person and so a Jewish perspective is that presumed consent diminishes the altruistic gift essence of organ donation and is

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perceived to diminish the status and respect with which the body / body parts are held after death.

The definition of “death” has been raised in each of the meetings I have attended and is of importance to many members of the Jewish faith for in the Chief Rabbi’s statement is the following

“In our discussion with medical professionals involved in the field it has become clear that organs are taken from people after death in two different scenarios. Either they are taken after irreversible damage to the brain stem, or after failure of the circulatory system (in common parlance described as “when the heart beat has stopped”). Both of these scenarios lead to respiratory failure (“when breathing has stopped”), and respiratory failure is an important factor in the definition of death in Halacha. There is a view that brain stem death is an acceptable Halachic criterion in the determination of death. This is the view of some Poskim (Halachicdecisors). However it is the considered opinion of the London Beth Din in line with most Poskim worldwide, that in Halacha cardio respiratory death is definitive.

Hence, in view of this, and of the significant Halachic issues relating to the procedure of the donation process itself, we believe that it is imperative that a competent Halachic authority should be consulted by families who find themselves involved in such discussions”.

Consequently, the preferred organ donation system is that families, including Jewish ones, should be able to consider and reflect, consult religious authorities if they so wish, and if they feel appropriate, give consent.

There is no definition of “death” in either the Bill or the Explanatory Memorandum of 3 December 2012 and this raises concerns. There is assistance regarding the role of the next of kin and careful consideration has been given to the wording of both documents to try and ascertain whether the concerns expressed in the meetings have been resolved.

Two paragraphs appear relevant. At paragraph 42 of the Memorandum it is stated that “under the new arrangements, very little will change in practice because the next of kin will still be asked to confirm details about the deceased’s health and lifestyle which might not be contained in their medical records and which could affect their suitability as a donor.” This clearly relates to suitability. It then refers to the separate issue of “consent” by confirming that “it is for the deceased to decide whether to opt in, opt out or have their consent deemed. The wishes of the deceased, whether it be through deemed or express consent should be made known to the family by NHS staff as part of the discussions. The legislation provides families with the right to provide information about whether the deceased would not have consented to their consent being deemed. Families will also continue to have an involvement in the process at a practical level”.

Paragraph 42 has to be read in conjunction with paragraph 44. This is intended to assist in understanding the role of the next of kin. Various scenarios are set out, the first of which relates to deemed or presumed consent and again confirms

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that “the deceased’s consent to donation will be deemed because they had the opportunity to express a wish not to be a donor (opt out) but did not do” and continues “However, the next of kin will be able to say whether they have any information that would lead a reasonable person to conclude that the deceased person would not have consented. This could include, for example, where the deceased had ever discussed the matter with them and expressed a view to the effect that they did not want to be an organ donor. Section 4(4) of the Bill provides that any person in a qualifying relationship, as set out at section 17(2) will be able to provide this information. It is not the intention to prescribe the type and quality of information which will fulfill this requirement, since this will be a matter of judgment in each individual case. However, examples of evidence could include details of conversations with the deceased which a person could reasonably believe took place; conversations which can be verified by another person; or other information which could be accepted as reasonable” but stresses that “in the context of providing this information, it is, as a matter of law, the wishes of the deceased which are relevant”. This is repeated by stating that “Where relations do not produce any information about the wishes of the deceased, then they will be in the position of knowing the deceased had not opted out, and had made no further wishes known. In these cases, the default position is that the deceased was in favour of donation and, as a matter of law, the deceased’s consent is deemed.”

It may be that our concerns are satisfied because paragraph 44 does contain this proviso “However this does not mean organ donation will automatically proceed as there will then be a discussion with the family about the donation process, including the medical history of the deceased. Clinical teams also have a responsibility to be sensitive to the views and beliefs of the surviving relatives in accordance with good practice guidance. This means clinical teams would not add to the distress of families by insisting on donation. It is important to be clear, however, that families do not have a legal veto because the law will recognise the deemed consent of the deceased as having precedence”.

It is further noted that in a “frequently asked question” section on the Welsh Assembly website the following paragraph is included under the heading “will there be a role for the family of the deceased in deemed consent cases?”

“Those close to the deceased therefore do not have a legal right to overrule the decision of the deceased to have their consent deemed. Clinical teams will nevertheless have a duty of care towards the family members and if there are very strong objections or distress then organ donation will not go ahead”.

This wording is different to that in the December 2012 Explanatory Memorandum as it refers to the clinical team having a “duty of care towards the family members’ and “if there are strong objections or distress, then organ donation will not go ahead” and it would be helpful to everyone if the wording in all published documents was identical but in a press release when laying the Bill before the Assembly the Health Minister, Leslie Griffiths, said, *“the role of the family is critical in informing the final decision on what happens to their relative’s organs. The wishes of the deceased are paramount and the vast majority of the people of*

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Wales do expect their wishes to be what really counts. For that reason, as is the case now, the family has no legal right to veto, but in practice a clinician would never add to their distress by insisting on donation". So according to the Health Minister whilst the Bill does not legally allow the family to have a legal veto the clinical team will, in practice, not insist on removal and, if she is correct, it seems that this will apply in situations where a deceased has decided to opt in.

It is therefore possible that our concerns whilst not overcome by the wording of the Bill might be covered by the extracts from the Explanatory Memorandum and Questions and Answers BUT the position of the Jewish Community is that stated in the Board of Deputies submission namely submission "organs are donated by individual Jews not by Jewish organisations" and perhaps I will change this to read "in Wales organs are donated by individual Welshmen and Welsh women and not by the Welsh Government".

11 January 2012