Health Committee call for evidence on the Human Tissue (Scotland) Bill

Response of the Scottish Council of Jewish Communities

In Halachah, (Jewish Law), the human body and all body parts and tissue are regarded as sacrosanct and should always be treated with dignity and respect. One manifestation of this is the requirement for quick burial, ideally within twenty-four hours of death. Before that mourning rituals cannot begin, and families cannot begin to come to terms with their loss. This is why Jewish people are anxious to avoid any procedure that might cause a delay, such as post-mortem examination. However, Halachah also mandates that the immediate saving of life takes priority over other laws, and thus permits organ and tissue donation in certain circumstances.

Halachah (Jewish Law) is very complex, and stipulates that each case of possible organ donation should be considered individually on its merits. As a general principle, religious Jews will wish to consult with a Rabbi before proceeding with organ donation and to feel assured that nothing is being done contrary to Halachah. Nonetheless, the Scottish Council of Jewish Communities generally welcomes the intention of the Human Tissue (Scotland) Bill. However we would urge that the draft Bill should be amended to provide clarification and reassurance on the following points.

Form of the legislation

We note that the Policy Memorandum accompanying the Human Tissue Bill states (section 4) that 'the provisions of the Bill relating to organ and tissue donation take account of ... the Executive's policy on organ donation and transplantation as set out in the Organ Donation Strategy for Scotland [and] the scrutiny of the existing legislation, the 1961 Act undertaken by both the Scottish Transplant Group and the Review Group on Retention of Organs at Post-Mortem' and that (section 5) both the Organ Donation Strategy and the Review Group on Retention of Organs at Post-Mortem 'called for the 1961 Act to be replaced by separate legislation governing organ and tissue donation on the one hand, and retention of organs and tissue at post-mortem examination on the other.'

As we have already stated, where there is any possibility of carrying out an immediate life-saving procedure for a patient, Halachah (Jewish Law) permits burial to be delayed and organs and/or tissue to be removed from a body for donation. There are, however, many complex issues involved and we would therefore support moves to ensure that the relevant legislation is not subject to confusion. We would question why the advice of the above expert review groups has not been followed and why the published Bill covers organ and tissue donation and transplantation, post-mortem, retention of organs at post-mortem and anatomical examination within a single piece of legislation.

Duties of Scottish Ministers

We recognise the importance of organ transplantation in the saving of life, and support initiatives to provide information, improve awareness and develop programmes in this regard. However, we have some concerns in relation to Part 1(1), 'It is the duty of the Scottish Ministers to promote, support and develop programmes of transplantation [and to] promote information and awareness about the donation for transplantations of parts of a human body', for which there seems to be no precedent - legislation does not lay a similar duty on Ministers in relation to promoting, developing and supporting programmes in relation to other recent legislation such as promoting charitable activity, promoting family life, the reduction of smoking, developing programmes for the management of offenders etc, and it is our view that there is no reason for this legislation to depart from the norm.

We are concerned that this duty could result in the development of policies which put individuals in a very vulnerable state and perhaps approaching death, under undue influence, or lead people to

believe that they do not have a genuine choice about donating organs or tissue, thus making it harder for them to refuse authorisation even if that is their preference.

Non-invasive Post-Mortem Examination

We would draw the Committee's attention to the use of non-invasive investigative procedures such as MRI scanning. This is already used in NW England as an alternative to some surgical post-mortem examinations. As has been the case with other new technologies, the cost of this procedure has already fallen significantly, and is likely to continue to fall rapidly leading to its increased use. Given the possibility that MRI post-mortems may be introduced into Scotland we suggest it would be appropriate for the Bill to make clear that many of its provisions relate only to surgical post-mortem examination. It is conceivable that some people might give authorisation for a non-invasive procedure whilst not doing so for a surgical post-mortem, and we recommend that the Bill should provide for this eventuality, and at very least refer explicitly to "surgical post-mortem" where that is what is intended..

Authorisation

We support the use of the term 'authorisation' as 'an active decision taken by someone in control' (Policy Memorandum section 40) but have some concern about the view that 'authorisation' is preferable to 'consent' because it 'can be given even if no information has been provided about what is being authorised' (ibid section 41). We appreciate that some people may not, for example, wish to know the detail of a surgical post-mortem examination, but we are uncomfortable with a policy that could be used to justify not even attempting to provide adequate information. Whilst good practice should ensure that this would not be the case we would prefer that the underlying policy of the Bill should unequivocally support the provision of information to the level required by the person or people concerned. An example of where this may be of particular importance is in cases where current medical practice differs from Halachah (Jewish Law) such as in the definition of death.

Means by which authorisation can be given and withdrawn

We note that authorisation of the removal and use of a part of an individual's body for transplantation can only be withdrawn in writing, although it can be authorised either in writing or verbally (in the presence of two witnesses). Similarly a person can give advance authorisation for a post-mortem examination either in writing or verbally (in the presence of two witnesses) but written authorisation can only be withdrawn in writing. Verbal authorisation for a post-mortem examination can be withdrawn either verbally or in writing.

Bearing in mind the possibility that someone may change his or her mind at any point we believe that the procedure for giving and withdrawing authorisation should be made as straightforward as possible at any time. This includes when a person may be very ill, perhaps approaching death when they may not be able to write or sign their name to a document although able to express themselves verbally. We therefore urge that this provision should be altered in the Bill to enable a person to withdraw authorisation for organ donation, post-mortem examination and anatomical examination either verbally or in writing regardless of how authorisation was originally given.

People who can give authorisation for a child

In the case of a child under the age of 12 years old the Bill specifies that someone who, 'immediately before the death ... had parental rights and parental responsibilities in relation to the child' can authorise the removal of a part of the body for transplantation and/or can authorise a post-mortem examination. The Policy Memorandum (Section 50) refers to 'a parent' giving authorisation, and states that 'if that parent wishes to authorise a hospital post-mortem examination, it seems reasonable that those wishes should not be thwarted ... because the other parent cannot, for whatever reason, be contacted at the time'.

We would like to draw the Committee's attention to the Family Law (Scotland) Bill, (Stage 1 report published July 2005). It seems probable that the Family Law Bill will widen the range of people with parental rights and responsibilities in relation to a child and this may have implications for the Human Tissue Bill. For example, as it stands, the Bill would permit anyone with parental rights and responsibilities in relation to a child to give authorisation without either parent necessarily having to give authorisation – or even having to be asked to do so. We strongly recommend that there should be an obligation on the hospital at least to make an attempt to contact both parents and to determine and take account of their views. (In case of disagreement between parents the Policy Memorandum (section 50) vests the decision in the hands of the hospital which 'should be able to take a pragmatic decision'. We do not believe that this should be the case, and urge the Committee to consider the effect that other legislation might have on this Bill.)

Hierarchy of relatives who can give authorisation for an adult

We have some concerns over the determination of a person's nearest relative as set out in the Bill (section 45). In particular, we do not believe that age should be the main determinant when there is more than one person in a single category of the listed hierarchy. The Policy Memorandum (sections 27, 55 and 81) highlights the importance of respecting and being sensitive towards the religious views of the family. However, as it stands the Bill would allow the eldest child of the deceased adult to give authorisation regardless of any objections on religious or other grounds from one or more younger siblings. Similarly a step-child of the adult who is older than the adult's biological child or children could give authorisation regardless of any religious objections that they might have.

We are strongly of the view that the Bill should be more flexible in this respect than it is at present in order that strongly-held religious beliefs can be taken into account. Further, and in order to respect people's sensitivities at what is necessarily a highly emotional time, we would suggest that if **any** close relative objects to post-mortem examination or donation of organ or tissue on religious grounds then the procedure should not go ahead.

Summary

Halachah (Jewish Law) requires that a person's body and organs should be treated with dignity and respect at all times and we therefore support the intention of the Human Tissue Bill in ensuring that proper authorisations are obtained before proceeding with post-mortem examination and/or organ and tissue donation and transplantation. We do, however, believe that some parts of the Bill require further consideration to ensure that the Policy Memorandum objective of respecting religious views is met.

Note: The Scottish Council of Jewish Communities is the representative body of all the Jewish communities in Scotland comprising Glasgow, Edinburgh, Aberdeen and Dundee as well as the more loosely linked groups of the Jewish Network of Argyll and the Highlands, and of students studying in Scottish Universities and Colleges.

In preparing this response we have consulted widely among members of the Scottish Jewish community, particularly those involved in the healthcare professions.