

The Human Tissue (Scotland) Bill and Issues relating to Adults with Incapacity Response of the Scottish Council of Jewish Communities

As noted in the Scottish Council of Jewish Communities' previous evidence relating to the Human Tissue Bill, Halachah (Jewish Law) regards the human body and all body parts and tissue as sacrosanct, and requires that they must always be treated with dignity and respect whether or not the deceased had legal capacity. We are concerned about possible exploitation or abuse in situations where the deceased did not have capacity, and welcome the opportunity to respond to this consultation.

Organ donation

Whilst Halachah (Jewish Law) mandates that the immediate saving of life requires priority over other laws, these rules are very complex, and therefore each case of possible organ donation should be treated individually on its merits. Religious Jewish people will, therefore, generally wish to consult with a Rabbi before proceeding with organ donation.

Q1. Is there any reason why the authorisation proposed for adults in general by the Bill should not apply to adults with incapacity, provided they had the capacity to make that decision at the time they started to carry an organ donor card or put their name on the NHS Organ Donor Register?

and

Q2. Does the fact that the adult may subsequently lose capacity, and therefore the capacity to withdraw an existing authorisation, raise any separate issues?

In our earlier evidence, the Scottish Council of Jewish Communities questioned the requirement for a person to withdraw authorisation for organ or tissue donation in writing although the Bill provides for authorisation to be given either verbally or in writing. We note that the Deputy Minister for Health and Community Care responded to this question in the Health Committee:

The position in relation to transplantation is that withdrawal of authorisation must be done in writing. That is because once authorisation has been given, we want to avoid any confusion or lack of clarity about the intention of the adult in question. The adult gives their authorisation in advance. We want to ensure that the clinician is protected from any ambiguity about withdrawal of authorisation. (Official Report 25 October 2005)

Whilst also naturally concerned that the clinician should be protected, our main concern is precisely to avoid 'confusion or lack of clarity' about whether or not the adult in question did indeed give authorisation in advance which is no more or less certain than a possible subsequent change of mind. We do not believe there is any reason why different standards of evidence should apply for giving and withdrawing authorisation.

We do not suggest that an adult who has lost capacity subsequent to authorising organ or tissue donation should be barred from becoming a donor, but we urge that there should be a presumption s/he might have withdrawn authorisation had s/he been able to do so, and that donation should only take place if the deceased's relatives give authorisation.

Q3. Should the Bill be used to put beyond doubt in future the issue of a welfare attorney or guardian's powers to give authorisation for the donation of body parts after the adult's death where the adult with incapacity was known to have expressed a view as regards donation before losing capacity? If this should be possible, what proof, if any, should the welfare attorney or guardian be expected to provide of the donation wishes of the adult with incapacity?

We do not agree with the proposition in section 8 of the consultation document permitting, *'the welfare attorney or guardian [to sign] an organ donor card on behalf of the adult with incapacity, or [put] the name of the adult with incapacity on the NHS Organ Donor Register'*.

In our view the procedure following the death of an adult with incapacity should be no different from that following the death of any other adult who had not authorised in writing organ or tissue donation, namely that authorisation should have to be given by the appropriate relative(s), who should, so far as possible, respect the known wishes of the deceased.

Q4. Does the fact that an adult who has lacked capacity for many years prior to death unduly prejudice the incapable adult, contrary to the spirit of the 2000 Act, when compared to any capable adult, as regards the opportunity to change their mind about donation?

Should the length of time an adult has lacked capacity render invalid any wishes in favour of donation which they had expressed while they still had capacity? If so what would the appropriate length of time be?

We do believe that the incapable adult may be at a disadvantage as compared to a capable adult in this regard – particularly if any change of mind is required to be put in writing. In order to respect people's sensitivities at what is necessarily a highly emotional time, we would suggest that if the incapable adult or any close relative objects to organ or tissue donation then the procedure should not go ahead. Whilst the length of time that an adult has lacked capacity clearly has a bearing on the emphasis that should be placed on their previously expressed view, we do not believe it is appropriate to set a time limit within which that view can be acted upon without additional authorisation from relative(s).

Q5. Is there any problem with the role of the nearest relative of an adult with incapacity in respect of the fact that the nearest relative could in theory authorise the donation of body parts from a person who was an adult when they died but had never had capacity in life to express any wishes on the subject themselves?

We do not believe that this raises any additional problem. As suggested in section 14 of the consultation paper, the responsibility of the adult in this respect would be similar to that towards a child under the age of 12 for whom s/he had parental responsibility.

We do, however, have some concerns about the hierarchy of relatives who can give authorisation as set out in the Bill. We strongly believe that the Bill should be more flexible in this respect, and that, in order to respect people's sensitivities at what is necessarily a highly emotional time, that organ or tissue donation should not go ahead if any close relative objects.

Q6, Are consultees generally in favour of the prohibition of the removal of organs, parts of organs and non-regenerative tissue from a living adult with incapacity for the purpose of transplantation to another person? If not, should consideration be given to making the position in Scotland consistent with that proposed for the rest of the UK, ie a mechanism should be put in place to allow the Human Tissue Authority to consider the donation of organs, parts of organs or non-regenerative tissue by a living adult with incapacity?

We are extremely concerned that legislation permitting living donation of organs and non-regenerative tissue by adults with incapacity could be exploited and could lead to abuse. We do not agree with the argument referred to in section 24 of the consultation document '*that adults with incapacity should not be denied the opportunities for altruism which are available to other adults*' and support the view of the Executive, stated in section 25 that '*organs, parts of organs and non-regenerative tissue should not be allowed to be removed from a living adult with incapacity for the purposes of transplantation*'. To call this altruism is an abuse of language. Altruism must be voluntary; otherwise it is an abuse. A person with the capacity to be altruistic has the capacity to decide whether or not to make a donation; a person who lacks that capacity cannot by definition be altruistic.

We do, however, recognise that a donation from a living donor with incapacity may be the only way to save a life, and suggest that there should be an appropriate judicial procedure for determining such difficult cases.

Q7. Do you agree that it should be possible for adults with incapacity to donate regenerative tissue, subject to independent scrutiny of each case?

and

Q8. Should adults with incapacity be able to donate regenerative tissue only to close family members or should non-directed donation also be open to them?

Whilst we would agree that there may, subject to stringent safeguards and with independent scrutiny in each case, be justification for permitting adults with incapacity to donate regenerative tissue, we do have concerns about the arguments advanced in section 26 of the consultation paper. In our view, the suggestion that adults with incapacity who give living donations might receive benefit by '*overcoming the limitations created by incapacity*' could be stretched to permit other procedures, including those clearly exploitative and abusive of the incapable adult. In order to limit the possibility of this occurring, we recommend that living donation of regenerative tissue from adults with incapacity should only be permitted where the recipient is a close family member.

Q9. If the donation of regenerative tissue from an adult with incapacity is to be possible, should the case by case scrutiny be provided:

- a) by conferring a function on the Scottish Ministers so that they can refer cases to the Human Tissue Authority, as will happen in the rest of the UK; or
- b) by adapting the protections in relation to research which are already incorporated in the Adults with Incapacity (Scotland) Act 2000, including an appeal provision?

In the latter case, should there be a provision that such tissue could not be removed unless there was no donor with capacity who was a suitable match?

We do not have a view as to the best means of scrutinising possible cases of living donation of regenerative tissue by adults with incapacity but believe that there should be a presumption against donation and that scrutiny should take place at the highest possible level. We do, however, believe that, where there is a suitable match, it is preferable to use a donor with, rather than without capacity

Q10. Is there any reason why the authorisation arrangements proposed for adults in general in relation to decisions relating to post-mortem examinations or the Anatomy Act 1984 should not apply to adults with incapacity?

Jewish people are anxious to avoid any procedure, such as post-mortem examination, that might cause a delay to burial. This is because Halachah (Jewish Law) requires quick burial, ideally within twenty-four hours of death out of respect for the human body. Mourning rituals can only begin after the burial, and any delay prevents families from beginning to come to terms with their loss.

Because of the possibility that an individual might have withdrawn authorisation for a hospital post-mortem examination and/or for the use of their body for the purposes of training or research, we do not believe it is appropriate to rely on an authorisation made prior to an adult losing capacity. In such situations we strongly recommend

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that a post-mortem examination should not be undertaken without additional authorisation from close relative(s).

We would like once again to draw attention to the possibility of non-invasive post-mortem procedures such as MRI which is currently being used in NW England. We consider it likely that some people may be willing to give authorisation for a non-invasive procedure when they would not do so for a surgical post-mortem examination.

Summary

The Scottish Council of Jewish Communities supports the general intentions of the Human Tissue Bill in ensuring that proper authorisations are obtained before proceeding with post-mortem examination or organ or tissue donation. We are concerned that some of the proposals relating to Adults with Incapacity weaken that intention, and would permit these procedures despite doubtful, uncertain or merely presumed authorisation. In our view the proposals arise from a desire to increase the number of organs available for transplant, but we would be extremely concerned if this were to be achieved at the cost of a reduction in the level of required authorisation.

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.