

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Give and take? Human bodies in medicine and research between April 2010 and July 2010. The views expressed are solely those of the respondent(s) and not those of the Council.

Donor Family Network

Question 1

The advent of the first face transplant in the UK will bring with it a range of new ethical issues.

Question 2

Facial transplants would be considered as 'special' as the face can in theory be 'seen' by others whereas internal organs cannot. Although there are no issues linked to recognition of the donor in a face transplant public perceptions may be an issue

Question 3

Donation after death is altruistic whereas in reality in the UK at the present time altruistic living donation is a relatively rare occurrence. Living donation tends to be through someone related or known to the recipient.

Question 4

Deceased donation of solid organs and/or tissue presents no risk or cost to the donor or to their family. However, the benefits to the family are immense. Agreeing to organ donation at the time of the death of a loved one can: a) give control back to the family via the request and consent process at a time when they may feel they have no control of the situation at all b) provide hope and purpose in an otherwise futile situation - 'death was not in vain' c) instills a sense of great pride in having saved/enhanced life through the gift of organ donation. d) many families feel they have not only saved lives but prevented another family from going through the experience of the death of a loved one

Question 5

Not relevant to our organisation

Question 6

Organ and tissue donation after death is viewed as an unconditional gift although in some, albeit rare cases, families will raise specific concerns a) organs/tissue being given to someone from a different ethnic/cultural/religious background b) organs/tissue being given to someone who has been convicted of certain crimes - murder, child crime etc c) organs, particularly lungs and liver, being given to smokers and alcoholics Some families may request 'directed donation' if they know of a relative or close friend who is in need of a transplant. Ethical concerns for the donor would also arise where the organ has been procured financially.

Question 7

In the case of organ and tissue donation life saving, life prolonging and life enhancing would be the main areas of priority. Some qualification may be required as to the definition of life enhancing ie does that include cosmetic reasons?

Question 8

Not applicable to our organisation

Question 9

Generosity

Question 10

Altruism Dignity Autonomy Generosity In the case of organ and tissue donation these are of equal importance

Question 11

Morally it is wrong to expect compensation, particularly financial, for deceased organs or tissue. There should be no difference between types of organs or tissue in this instance.

Question 12

There is some argument that everyone has a duty to donate organs and tissue after death so long as there is a need within society for those organs and tissue. However, morally everyone has the right of autonomy to decide their wishes for their organs and tissues, this includes the right to say no to donation.

Question 13

Not applicable to our organisation

Question 14

Where demand means that people are suffering or dying then yes, it is right to try and meet demand. But there should be limits to avoid coercion and financial exploitation of the bereaved.

Question 15

Bereaved families want recognition not compensation. Money cannot replace a loved one. Incentives could be seen as morally wrong in this area.

Question 16

Non-financial tokens of gratitude are welcomed by donor families in the form of things such as pin badges and certificates etc. No financial recompense can bring

back a loved one after death and many consider this concept to be insulting. Non-cash incentives are appropriate for promotional purposes. It is difficult to state if incentives would be effective in this scenario but indications are that they would not. It is also difficult to see how an incentive offered by friends or family would apply to deceased donors.

Question 17

Many families may be discouraged by the idea of benefiting financially from the death of a loved one. This may have a counter productive impact as families may be less likely to agree to organ donation.

Question 18

In some countries funeral expenses are paid by the state in the case of deceased donation, but when such practises have been debated previously in the UK they have been criticised as providing organ donors with a 'reward' Indirect compensation may be viewed more positively but would need to be comprehensively researched.

Question 19

Factors such as loss of earnings, discomfort and inconvenience do not apply in the same way to donor families; they are the inevitable outcomes of bereavement.

Question 20

Uncontrolled donation after cardiac death may increase the organ pool but could potentially be more difficult for families (and healthcare professionals) to come to terms with.

Question 21

Incentives and 'encouragement' remove dignity, generosity and altruism from the act of organ donation. These are values which are highly prized by bereaved families.

Question 22

Does not really apply to deceased donation, although there may be disagreement between family members.

Question 23

No

Question 24

In many ways it can be harder to make a decision on behalf of someone else as the views and wishes of that person may not be known or understood.

Question 25

This is a complex issue, particularly in light of the Human Tissue Act. a) where a deceased persons wishes are known all efforts should be made to facilitate donation. However, donation should not go ahead if it is felt that this would cause unnecessary pain and suffering to a bereaved family who have raised objections following detailed discussions with an appropriately trained healthcare professional. More public education and promotion is required to ensure that families discuss their wishes relating to organ donation prior to their death. b) where the deceased persons wishes are not known then consent should rest with the family, and the person in the family who knew that person best, following detailed discussions with an appropriately trained healthcare professional

Question 26

If a body should be owned after death it should belong to the deceased's next of kin unless circumstances dictate that the body falls under the remit of HM Coroner or the Procurator Fiscal.

Question 27

If you have a right to sell do you therefore have a right to buy? This then becomes a socio-economic issue where the wealthy can afford to pay and the poor need to sell to survive and the opposite way around will not happen.

Question 28

Many families would be in favour of limited directed donation - where a family member or close friend can benefit from your organs and/or tissue following your death. All families have a right to be asked about donation at the time of the death of a loved one - this should not be affected by personal views or opinions of the health care professionals involved and should be viewed as part of the end of life care given to the dying.

Question 29

The future use of organs and tissue should depend on the nature of its use and on the consent given at the time. Life saving or prolonging would usually be acceptable but things such as research may not.