

Organ donation from infants with anencephaly — guidance from the UK Donation Ethics Committee

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The role of The UK Donation Ethics Committee

- 1 The UK Donation Ethics Committee (UKDEC) is an independent body, hosted by the Academy of Medical Royal Colleges (the Academy), and funded by all four UK Health Departments. UKDEC's role is to consider ethical issues relating to the field of organ donation and transplantation and to provide independent advice to clinicians, policy leads and others.
- 2 UKDEC was established in January 2009, following a recommendation by the Organ Donation Task Force (ODTF) that:

'Urgent attention is required to resolve the outstanding legal, ethical and professional issues in order to ensure that all clinicians are supported and are able to work within a clear and unambiguous framework of good practice. Additionally, an independent UK-wide Donation Ethics Committee should be established.'

Definitions

Anencephaly

- 3 A neural tube defect (NTD) that occurs when the cephalic (head) end of the neural tube fails to close, usually between the 23rd and 26th days of pregnancy, resulting in the absence of a major portion of the brain, skull, and scalp. Anencephaly is a very rare diagnosis, with only a small number of anencephalic babies being carried to term each year in this country. Approximately a third of these babies will not breathe at birth, and all die in the neonatal period.

Death

- 4 Death entails the irreversible loss of those essential characteristics which are necessary to the existence of a living human person. The definition of death should be regarded as the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe.
- 5 The diagnosis and confirmation of death may be made using either circulatory criteria after cardiorespiratory arrest, or neurological criteria. The procedures required to satisfy these criteria are set out in the 2008 Academy of Medical Royal Colleges' *Code of Practice for the Diagnosis and Confirmation of Death* (hereafter referred to as the Academy Code of Practice). Specific guidance on the diagnosis of death by neurological criteria in infants between 37 weeks and two months corrected gestational age was issued in April 2015 by the Royal College of Paediatrics and Child Health.¹

Donation after brainstem death (DBD)

- 6 The familiar acronym for donation after brain stem death is DBD. It is commonly used to describe deceased organ donation following the confirmation of death using neurological criteria as set out in the Academy Code of Practice.

Donation after circulatory death (DCD)

- 7 The familiar acronym for donation after circulatory death is DCD. It is commonly used to describe deceased organ donation following the confirmation of death using circulatory (cardio-respiratory) criteria as set out in the Academy Code of Practice. In December 2011, UKDEC also published *An ethical framework for controlled donation after circulatory death*.

Introduction

- 8 UKDEC has been approached for advice about the ethical issues surrounding organ donation from infants with anencephaly. Whilst this document focuses on pregnancies and infants that are affected by anencephaly, the principles might equally apply to other prenatally diagnosed abnormalities that are associated with death in the newborn period.
- 9 This document reflects UKDEC's understanding of the legislation governing decisions about organ donation. However, any clinician with practical concerns about the impact of the various pieces of legislation on their decision-making should seek their own independent legal advice.
- 10 Donation from infants with anencephaly is rare in other countries and UKDEC is not aware of any recent examples outside the UK. The last documented case outside the UK is from 1999 in Italy.² UKDEC is aware of a small number of cases of donation from infants with anencephaly in the UK, and was approached by the clinical team for ethical advice in relation to another case where donation did not proceed for clinical reasons.
- 11 Despite the rarity of anencephaly, there are clearly some parents of infants with anencephaly who value the opportunity to donate organs, and we hope that this guidance will support parents and practitioners to make confident decisions about donation and its implications for the care of mother and baby, and manage the legal and ethical challenges posed by donation in these tragic circumstances.

Background and existing advice

12 In its position paper on ethical issues in paediatric organ donation,³ UKDEC concluded:

- *It would be ethically acceptable for organ donation from infants with anencephaly to proceed with the consent of the parents after death has been confirmed by circulatory criteria*
- *The parents' values and beliefs should be allowed to determine whether their child is intubated and ventilated, provided this is not against the child's interests. Precautionary sedation and analgesia would be needed to ensure this condition is met.*

13 In reaching these conclusions, the position paper observed that:

- *DBD is not an appropriate donation pathway for anencephalic infants, as the brain stem is usually preserved and some degree of brain stem function will often be present. Additionally the absence of large parts of the brain means that the standard tests cannot meaningfully be interpreted for death to be safely confirmed using neurological criteria*
- *DCD could be considered in such cases but this would require either a surgical organ retrieval team in readiness at the birth or elective intubation of the infant at the time of birth to allow donation options to be explored over the coming hours. As for any potential donor, interventions to facilitate DCD from infants with anencephaly should be seen on a spectrum, with intubation and ventilation being one of the most invasive.*

Issues faced by decision-makers

- 14 Having established in principle that organ donation from infants with anencephaly can be ethically acceptable, and that some interventions aimed at facilitating donation might be appropriate as long as they are not against the child's interests, we turn our attention to identifying the specific issues faced by practitioners and parents in making these decisions.

Is deceased donation from an infant with anencephaly ethically acceptable?

- 15 With regard to donation there is no intrinsic difference in practice between an infant with anencephaly and any other infant. Donation is permissible after death has been diagnosed and confirmed providing the appropriate consent (or authorisation) is given.
- 16 As is the case with any newborn, the infant's interests would need to be conceptualised and expressed on their behalf – most usually by their parents. The interests of the infant become part of an account of the interests of the family as a whole, but it should be possible to show that a family has given due respect to the interests of their child in deciding to donate.

Deciding to donate

- 17 Donation from infants with anencephaly is difficult, and the likelihood of a successful transplant may be limited. Despite this, some parents may see organ donation as a positive experience in a tragic situation, and a way of allowing their child to leave a legacy. Donation from infants with anencephaly should be considered when the child's parents express the wish to donate, but it is not current practice to suggest donation unless the parents raise it themselves.
- 18 The idea that their child's organs might mean a better life for others, especially other children, might be a major factor in their decision to donate their child's organs. It is therefore important that they are supported in their decision by adequate and accurate information about the donation process and what it entails. This should include an honest appraisal of the likelihood of a donation proceeding to a successful transplant. Factors to be considered include:
- The organs may not be sufficiently mature to be suitable for transplantation, particularly if delivery is brought forward in the interests of the mother
 - There may be no suitable recipient at the time organs are offered for donation
 - Because donation from infants with anencephaly must be DCD, parents must be made aware of the uncertainties inherent in the DCD pathway
 - Organs at present often go to an adult rather than to a child
 - There is a significant risk that the child may die during or just after delivery (especially if natural birth is chosen rather than Caesarian Section)
 - BUT if the donation did take place satisfactorily, it would bring benefits not only to the recipient(s), but to the donor family as well, enabling them to achieve a more positive outcome from a very difficult situation
 - If transplantation is not possible, the donation of organs for research purposes may be an option that the donor family may wish to consider.
- 19 Because of the implications for the care of the mother and baby, discussions about donation from anencephalic infants will inevitably take place over a longer period of time than other donations involving children or neonates without a prior diagnosis of severe fetal anomaly. The family's feelings and wishes could change over time and it would be equally important to discuss the possibility of end of life care strategies that did not include donation.

Impact on care during pregnancy & birth

- 20 Everything possible should be done to ensure that the parents' experience of the baby's death is as positive as it can be under the circumstances. If parents decide they want to donate their baby's organs, this will inevitably affect decisions about the care of mother and baby during pregnancy and birth.
- 21 For example, a decision about whether birth by caesarean section is appropriate may be influenced by the parents' wish to donate organs. Factors that may affect their decision include the risk of intrauterine death in labour, and the need for the birth to be timed to link with presence of the transplant team. The urgency of the organ retrieval process may also limit the opportunity for skin-to-skin contact between baby and mother, or for the mother to hold her baby.
- 22 Clearly organ donation will be only one factor in reaching such decisions, but if benefits in relation to organ donation form part of the decision-making, it is important to provide realistic information about the likelihood of donation proceeding to a successful transplant (see under "deciding to donate" above).

If the infant is born dead (showing no signs of life)

- 23 If the infant dies in utero, or is born showing no signs of life, then organ donation is not possible at present. If donation were a possibility (and assuming that resuscitation attempts would not be appropriate) then there are no ethical reasons not to proceed to donation under these circumstances assuming that appropriate consent or authorisation is given.

If the infant shows signs of life when born (i.e. has a heartbeat, and may breathe), but subsequently dies

- 24 If organ donation were not a consideration, then usual medical practice would be to consider only comfort measures to enable the infant to reach the end of his or her life without pain or distress.
- 25 DCD could be considered in such cases, but this would require either a surgical organ retrieval team in readiness at the birth or elective intubation of the infant at the time of birth to allow donation options to be explored over the coming hours. Interventions to facilitate DCD from infants with anencephaly should be seen on a spectrum, with intubation and ventilation being one of the most invasive.

Intubation and ventilation

- 26 In its position paper on ethical issues in paediatric organ donation UKDEC has argued that the parents' values and beliefs should be allowed to determine whether their child is intubated and ventilated, provided this is not against the child's interests.⁴
- 27 Whilst infants with anencephaly usually have an absent forebrain, there is limited data about whether they can feel pain or discomfort. Therefore potentially painful or distressing pre-mortem interventions such as intubation and ventilation must be accompanied by sedation and analgesia, as for any other infant. If clinical staff believe that despite the parents' wish to proceed with donation, the process is causing, or may cause, undue suffering or distress to the child, interventions should not proceed (for example, if there is no readily available vascular access, then clinicians may decide to stop before multiple venepuncture causes distress to the infant). There may be other benefits associated with intubation and ventilation, for example allowing the family to spend time with their child.

Withdrawing ventilation

- 28 When ventilation is stopped, death will inevitably follow. When a treatment (in this case ventilation) is not in the child's best interests, there is no legal or ethical obligation to continue it. *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice*, published in 2015 on behalf of the Royal College of Paediatrics and Child Health (RCPCH),⁵ sets out circumstances under which withholding or withdrawing life-sustaining treatment might be ethically permissible. Decisions about withdrawing treatment should be made in line with the RCPCH framework.

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