An ethical framework for donation after confirmation of death using neurological criteria (DBD)
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1. The role of UKDEC

1.1 UKDEC is an independent body, hosted by the Academy of Medical Royal Colleges, 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.

1.2 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.’
2. Terminology

**Death**

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.

**The diagnosis and confirmation of death**

This 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).

**Brain stem death (BSD)**

This is a term commonly used to describe death confirmed using neurological criteria.

**Brain stem death testing**

The mandatory procedure for confirming death using neurological criteria as set out in the Academy Code of Practice.

**DBD**

This is a familiar acronym for ‘donation after brain stem death’. 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.

**DCD**

This is a familiar acronym for ‘donation after circulatory death’. 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. UKDEC has published an Ethical Framework for DCD (An ethical framework for controlled donation after circulatory death: Academy of Medical Royal Colleges, December 2011. www.aomrc.org.uk/donation-ethics-committee.html)

**Overall benefit**

In this guidance we use the term ‘overall benefit’ when describing the course of action most appropriate to a particular patient at a particular time. This is in order to ensure that the points discussed may be applied to the legal frameworks throughout the UK. It follows the language used in the GMC guidance on end of life care. In this document, as in other UKDEC publications, equivalent terms, such as ‘best interests’, are only used when referring to a specific legal test.

**Patient/potential donor**

We have used the terms “patient”, “potential donor” and “donor” as sensitively as possible, within the relevant context.
3. The purpose of this document

3.1 The purpose of this document is to provide an ethical framework within which clinicians and others involved in donation and transplantation can make decisions with confidence. This document is intended to complement UKDEC’s 2011 publication, “An Ethical Framework for Controlled Donation after Circulatory Death”. Many of the ethical considerations identified in that document are also present when donation follows confirmation of death using neurological criteria, but some are specific to DBD and are dealt with in this framework.

3.2 UKDEC does not believe that DBD, as currently practised in the UK, presents many unresolved ethical problems. However, the main areas of ethical concern need to be revisited for the benefit of the public, for professionals unfamiliar with the field, and to ensure consistency between the standards recommended for DCD and DBD.

3.3 Although it is inevitable that some procedural issues are considered in detail in this document, it is not our intention to produce a restrictive clinical manual.
4. The legal context

4.1 In the UK, the Human Tissue Act 2004 (which applies in England, Wales, and Northern Ireland); the Human Tissue (Scotland) Act 2006; and the Human Transplantation (Wales) Act 2013 are the primary statutes governing decisions about donation after death.

4.2 Currently, in the UK, there is no statutory definition of death. However, case law has approved the confirmation of death using neurological criteria (BSD) [Re A (A Minor) [1992] 3 Medical Law Reports 303; Re A (A Child) [2015] EWHC 443 (Fam)]. Such confirmation requires two sets of tests of brain stem function to be conducted in accordance with the Academy Code of Practice. The patient must continue to be regarded as alive until the second set of tests has been completed. If both sets of tests confirm that the patient is dead, the time of death is then taken as the point when the first set of tests was completed.

4.3 Before death has been confirmed using neurological criteria, including the period of time between the two sets of brain stem death tests being carried out, the Mental Capacity Act 2005 in England and Wales, the common law in Northern Ireland and the Adults with Incapacity (Scotland) Act 2000 govern decisions about the care of a patient who lacks capacity.

4.4 While this document incorporates UKDEC’s understanding of the legislation governing decisions about organ donation in the UK, anyone with practical concerns about the impact of the law on their decision-making should seek appropriate legal advice.
5. The clinical context

5.1 DBD and DCD rates vary between countries. Evidence suggests this is due to different attitudes to end-of-life care and the local management of organ donation. DBD is the most common form of deceased organ donation in the UK. DCD is increasing in the UK but, at present, DBD results in more and, for some organs, more successful, transplants.

5.2 Organ donation after death occurs most commonly in patients who have sustained severe brain injury and whose breathing is being supported artificially in the intensive care unit or emergency department. At present, in the UK, only about 1% of deaths take place in this circumstance, and in practice not all such patients will be suitable donors, or will wish to donate.

5.3 Doctors use different sets of criteria for confirming death according to the clinical circumstances. Tests to confirm death using neurological criteria are used when a patient’s breathing and circulation are being maintained by means of mechanical ventilation, but the patient is nevertheless strongly suspected to have died. This method of confirming death was professionally accepted in the UK in 1979. Its use is not confined to potential organ donors, but at present most deceased organ donations in the UK take place after death has been confirmed in this way.
6. The context of UKDEC’s approach to DBD

6.1 UKDEC accepts that death may be confirmed using neurological criteria, in accordance with the Academy Code of Practice. So-called ‘brain death’ or ‘brain stem death’ is not a different quality of death, but rather an accepted term indicating how death has been confirmed.

6.2 UKDEC has established two guiding principles, which have been reproduced in other UKDEC publications. These are:

**Principle 1**
Where donation is likely to be a possibility, full consideration should be given to the matter when caring for a dying patient.

**Principle 2**
If it has been established that further life-sustaining treatment is not of overall benefit to the patient, and if it has been further established that donation would be consistent with the patient’s wishes, values and beliefs, consideration of donation should become an integral part of that patient’s care around the time of death (both pre- and post-mortem).

6.3 In the context of DBD, UKDEC interprets these statements as follows:

Principle 1 is applicable to patients who are believed to have died but whose death has not yet been confirmed using neurological criteria.

Once death has been confirmed using neurological criteria, mechanical ventilation and other intensive care interventions are no longer life-sustaining. However, as per Principle 2, it remains appropriate to establish whether donation is consistent with the patient’s wishes, values and beliefs, and where that is the case, then to consider donation an integral part of post-mortem care.

6.4 There are circumstances in which the issue of organ donation may be raised by or with a patient’s family (or very rarely the patient) before death has been confirmed using neurological criteria. In such a case, because the patient is still alive, Principle 2 as originally stated above, applies fully.

6.5 The Human Transplantation (Wales) Act 2013 establishes that residents of Wales will be deemed to have consented to donate their organs unless they have made a decision during life either to consent to, or not consent to, organ donation. When consent to donation is deemed, donation will be regarded as consistent with the dying patient’s wishes, values and beliefs, and consideration of donation should therefore be an integral part of their pre-and post-mortem care.
7. Benefits and harms associated with confirming death using neurological criteria

7.1 Most of the benefits and harms that might be associated with confirming death using neurological criteria apply whether or not the patient is a potential donor. The section below sets out possible benefits and harms which clinicians must balance, in each case, regardless of whether organ donation is a possibility.

Benefits

7.2 Neurological tests to confirm death (carried out in accordance with the Academy Code of Practice) establish whether a patient is alive or dead. This is of benefit to the family and to hospital staff, because it eradicates doubt. This is true whether or not the patient is a potential donor. If the patient is found to be alive, care for the patient and the family can be continued or adapted accordingly.

7.3 Confirmation of death using neurological criteria allows futile and/or inappropriate treatment to cease. This is not only a benefit for the patient and family, but also a benefit for wider society because it allows valuable resources to be used for other patients.

7.4 The test results clarify the clinical context in which discussions about donation can take place.

7.5 When donation is a possibility, for potential recipients of certain organs, confirmation of the donor’s death using neurological criteria increases the likelihood of a successful transplant, since the donor will continue to be ventilated and thus reduce the risk of ischaemic damage to organs which may occur in DCD following the withdrawal of treatment.

7.6 Where there is evidence that a person wanted to be a donor, certainty that death has occurred makes possible the fulfilment of that wish.

Harms

7.7 If the patient is still alive, it is theoretically possible that the act of carrying out neurological tests to confirm death may cause discomfort, damage or distress.

7.8 The time taken to conduct tests might increase the burden on the patient’s family.

7.9 Carrying out neurological tests to confirm death might seem unnecessary to the family. This may also increase their distress.

7.10 It is likely that most families will benefit from the removal of uncertainty as to whether their loved one is alive or dead. However, others may have difficulty facing the extinguishing of hope brought about by the confirmation of death, and may even perceive the process of carrying out neurological tests to confirm death as a threat.

7.11 Carrying out tests to confirm death using neurological criteria in accordance with Academy guidelines takes time and resources which might otherwise be of use to other patients.
8. Ethical issues in DBD

8.1 In patients where there is potential for DBD, ethical uncertainty and real or perceived conflicts of interest may arise:

- **Before and during testing to confirm death using neurological criteria**
- **After death has been confirmed.**

**Before and during testing**

8.2 There can be no ethical justification for testing to confirm death using neurological criteria unless there is a high level of clinical suspicion that the patient is dead. Such testing should only take place when a patient’s breathing and circulation are already being artificially supported, and when death is strongly suspected.

8.3 There may be circumstances in which there are clear family or patient-centred reasons not to pursue the confirmation of death using neurological criteria. In such circumstances it would be acceptable clinical practice to withdraw mechanical ventilation when such treatment is no longer of overall benefit to the patient, and confirm death by circulatory criteria.

8.4 It is possible, though highly unusual, that the neurological tests reveal that the patient is still alive. This outcome would not preclude re-testing for death at a later time if clinically appropriate.

**Ethical questions that might arise before and during testing**

8.5 *Is it acceptable for the knowledge of a patient’s wishes about organ donation to influence a decision about whether to carry out neurological tests to confirm death?*

8.5.1 Knowledge of a patient’s wishes, values and beliefs should play an important part in all clinical decision making.

8.5.2 Successful donation is not the only benefit that accrues from confirming death using neurological criteria (see section 7 above). Therefore testing to confirm death using neurological criteria in accordance with the Academy Code of Practice should be regarded as routine best practice in all appropriate patients, regardless of the possibility of donation.²

8.5.3 Where there is evidence that a patient wished to donate their organs after death, the benefits from fulfilling that wish should be taken into account in deciding whether testing is for the patient’s overall benefit. It follows that any harms that may accrue from testing need to be taken into account as well. There may be circumstances, for example when there is competition for limited resources, where in practice the justification for testing is less clear. In such circumstances, knowledge and evidence of an individual patient’s wishes regarding donation may influence the decision about whether to test.

8.6 *When a patient or their family has expressed a wish to donate, is it acceptable to conduct other clinical procedures (such as blood tests) aimed at facilitating successful donation before testing to confirm death using neurological criteria?*

8.6.1 UKDEC’s guidance on *Interventions before death to optimise donor organ quality and improve transplant outcomes*⁶ provides a framework for making decisions about interventions before death, taking account of what is known about the patient’s wishes, values and beliefs in relation to organ donation.
The guidance acknowledges that if the patient is known to have wanted to be an organ donor, then adjustments to their end of life care may be necessary or desirable in order to enable this to happen. It recommends that clinicians should take a balanced view of the risk of harm when considering particular interventions or courses of action, encompassing both the risk of physical harm, and the risk of doing wrong by not acting in accordance with the patient’s wishes.

When is it appropriate to establish whether a patient is on the Organ Donor Register (ODR), and when is it acceptable to raise the issue of donation with families?

The circumstances in which organ donation becomes a possibility for a dying patient vary greatly, and have been considered in UKDEC’s guidance on DCD. The framework for raising the matter with families is set out in NICE guidance, which makes it clear that discussions about organ donation with those close to the patient should only be initiated when it has been clearly established that they understand that death is inevitable or has occurred. Further guidance is available in NHSBT’s Best Practice Guidance on approaching the family of a potential organ donor. UKDEC does not believe that acquiring knowledge of ODR status at an early stage of a patient’s care has any ethical consequences beyond maintaining patient confidentiality.

However, patients, families and circumstances vary. Some families, particularly those who are supportive of donation, may ask about the possibility of donation before clinical staff would ordinarily initiate such a discussion. It is important that families should be free to discuss donation when it is right for them. Sensitivity and flexibility are required at this difficult time.

If it becomes apparent that the patient in life, or their family at the bedside, are opposed to donation, should tests to confirm death using neurological criteria take place?

Even when donation is not likely, there are sound reasons for confirming death using neurological criteria. See section 7 above.

Should clinicians seek to confirm death by neurological criteria even if the family, or the patient in life, do not accept those criteria?

While the patient is still alive, the care of a patient who lacks capacity must be of overall benefit to the patient. Whilst there is no legal requirement to seek consent from the patient’s family for diagnostic tests, clinicians are required to consult those close to the patient to ensure that all relevant evidence about the patient’s wishes, values and beliefs is taken into account in making the decision about whether to test.

In making a decision about whether to confirm death by neurological criteria when those criteria are not accepted by the family (or the patient in life), clinicians will need to balance the strength of evidence that the patient wished to be a donor alongside other potential benefits and harms, including potential harms to the family.

Once it has been decided that testing is of overall benefit to the patient, family objections need not be a barrier to testing. Clinicians should consider offering families the opportunity to observe the neurological tests to confirm death being carried out. A careful and sensitive explanation of the methodology of and certainty provided by the tests should be provided as a matter of good clinical practice. Where appropriate, support from a member of the family’s cultural or religious community should be facilitated.
When death is strongly suspected, is it acceptable to keep a patient on mechanical ventilation and other intensive care support in order to enable testing to confirm death using neurological criteria to take place?

In some circumstances it may be difficult or inappropriate, for clinical or staffing reasons, to conduct tests immediately even though death is strongly suspected. The Academy Code of Practice sets out clear preconditions that must be fulfilled before testing can commence, and makes it clear that any confounding factors should be removed. For example, sufficient time must elapse for any sedative drugs administered as part of the patient’s treatment to clear from the patient’s body to ensure that the neurological condition is not reversible.

The benefits and harms to be balanced in such circumstances include the potential harm to other patients of using valuable resources for a patient with no hope of recovery, and the potential benefit to the prospective donor and recipients of maximising the chances of successful transplantation.

Any delay might cause harm in the form of distress to families, either by prolonging uncertainty as to whether their loved one is alive or dead, or, for some, by giving false hope of recovery.

Sensitive, open and transparent discussion with the patient’s family is likely to help clinicians arrive at the appropriate on-going management plan. As stated in Section 7, there are benefits and burdens associated with confirming death using neurological criteria. The clinical team should take into account what is known about the patient’s wishes, values and beliefs regarding donation. If the patient wished to be a donor, then improving the likelihood of a successful donation by extending their time on artificial support, though not of direct therapeutic value, may be of overall benefit to the patient.

There may be circumstances in which DCD could be offered if the delay to allow the preconditions for testing to be met is felt to be unacceptable. If this route is chosen, the family should be made aware of the possible limitations to their loved one’s donation that may be caused by such a choice.

Allowing time for the necessary preconditions for testing to confirm death using neurological criteria to be met is likely to be of overall benefit to the patient, and might bring benefits in the form of more successful transplants, but practical resource constraints and potential harms to the family should be taken into account. In the absence of strong constraining factors, allowing time for test preconditions to be met is acceptable.

Is it acceptable to move an intubated and ventilated patient to an intensive care unit (ICU) for testing to confirm death, and thus facilitate DBD donation?

If the ICU is the only place in which tests to confirm death using neurological criteria can be carried out on a patient who is already intubated and strongly suspected to be dead, then it is acceptable to move a patient to the ICU. In rare cases the tests might reveal that the patient is still alive, in which case ICU would be an appropriate setting in which decisions about their future treatment, or withdrawal of treatment, can take place.

Even so, care must be taken not to raise false hope in the minds of the family, who might suppose (because of the term ‘intensive care’) that immediate therapeutic treatment, rather than diagnostic tests, is planned.
8.11.3 For patients who are already intubated, admission to ICU for the purposes of testing to confirm death using neurological criteria is acceptable. However, it is appropriate to consider the competing demands on intensive care facilities. The needs of potential donors must be weighed against those of other patients needing access to intensive care facilities.

8.11.4 Interventions to stabilise a patient to facilitate neurological testing are routinely required and are likely to be acceptable, unless the degree, complexity and duration of the interventions are excessive or likely to compromise continuing supportive treatment.

8.12 **Is elective ventilation acceptable?**

8.12.1 Elective ventilation is the instigation of invasive ventilation for the sole purpose of facilitating organ donation with no expectation of therapeutic benefit for the person ventilated. UKDEC prefers the term non therapeutic elective ventilation (NTEV).

8.12.2 The use of NTEV was described in the academic literature and in the press in the early 1990s, but was then discontinued following legal advice obtained by the Department of Health in 1994 that its use was unlawful.

8.12.3 There have however been major changes in the law since then, particularly in relation to defining what is in the best interests or for the overall benefit of an individual. Re-examination of the practice now might lead to the possibility that NTEV could be lawful in some cases. Clinical practice has also changed and many more patients are now intubated and ventilated than was the case in the early 1990s, so there is less scope for NTEV.

8.12.4 UKDEC’s generic guidance on *Interventions before death to optimise donor organ quality and improve transplant outcomes* could be applied to NTEV to determine its suitability in individual cases. NTEV is, however, fraught with many difficulties and concern remains that NTEV could be harmful in some circumstances.

8.12.5 The debate about NTEV has become unproductive because of the perception that it is unlawful. That perception is driven by legal advice that is no longer reliable because the legal context has changed. Although the barriers to the use of NTEV are so large that it could not yet be readily recommended, its use should be re-examined. UKDEC has published a discussion document on NTEV, which sets out the legal and clinical changes in more detail.

**After death has been confirmed**

8.13 As stated in Section 6.3, once death has been confirmed using neurological criteria, mechanical ventilation and other intensive care support can no longer be regarded as life-sustaining. However, it will still remain appropriate to continue ventilating the patient in order to establish whether donation is consistent with the patient’s wishes, values and beliefs, and if so, to consider donation an integral part of post-mortem care.

8.14 If the patient’s wishes, values and beliefs regarding donation are not yet established, or agreement with the family has not been reached, it is acceptable to maintain intensive care support while a decision regarding donation is made.
8.15 Ethical questions that might arise after death has been confirmed

Is post-mortem organ optimisation acceptable?

Before consent or authorisation has been established

8.15.1 Where the wish to donate has yet to be established, actions aimed at maintaining the possibility of donation should consent or authorisation be obtained need to be considered on a case-by-case basis. There may be some low-risk actions that might be taken to increase the likelihood that donation can occur or reduce the time the donation process might take, should consent or authorisation be obtained. However, any interventions that present a significant risk of harm are unlikely to be justified in these circumstances. It is of course vital to keep families fully informed and take account of their views and concerns during this period.

8.15.2 Actions where the primary intention is to keep open the possibility of donation through stabilising the physiology of the potential donor, rather than optimising organ quality or suitability for transplantation, are likely to be acceptable.

Once consent or authorisation has been established

8.15.3 The interests of the deceased patient extend beyond the confirmation of death. When consent or authorisation for donation has been given, organ optimisation helps to ensure successful donation and transplantation.

8.15.4 When consent or authorisation for donation has been given, clinicians must still assess the balance of potential benefits and harms of any intervention proposed to maintain organ quality after death.

8.15.5 Once the patient is dead, the concept of clinical harm can no longer be relevant. However other potential harms remain, and include the risk of causing distress to the patient’s family, which may be affected by factors such as the level of intrusiveness of the intervention, or the impact on their ability to spend time with their deceased loved one. Ways of minimising this distress should be explored through careful explanation of both the need for particular interventions in order to facilitate the patient’s wish to be a donor and what is involved in those interventions. Interventions must not compromise respectful treatment of the deceased. In particular, the deceased’s cultural and religious views in life must be respected. Those caring for the patient must also ensure that interventions are carried out as respectfully as possible to the patient’s family and friends.

8.15.6 As transplant science and clinical practice evolves, new techniques to optimise organ quality and maximise the number of organs that can be retrieved will inevitably emerge. The ethical acceptability of applying such novel techniques will need to come under scrutiny, applying the principles adopted in this document. Moreover, the acceptability of existing techniques may need to be re-assessed in the light of new research.

8.15.7 Post-mortem organ optimisation is acceptable and usually justified when consent or authorisation for donation has been provided. Interventions must be evaluated individually, balancing the benefits against any potential harm to the donor and/or their family, and must be carried out as respectfully as possible to the patient’s family and friends.
8.16 Is external cardiac massage acceptable after the confirmation of death using neurological criteria for the purpose of organ preservation in a patient for whom there is consent or authorisation for donation?

8.16.1 During the wait for organ retrieval a potential donor can sometimes become haemodynamically unstable and suffer a cardiac arrest. In such circumstances cardiac massage and other resuscitative measures might allow the option of organ donation to be preserved where it would otherwise be lost. However, it can be distressing for families and staff, and may compromise the respectful treatment of the patient.

8.16.2 Clinicians faced with this situation should balance the strength of the known wish to donate with the degree, complexity and duration of the proposed cardiac massage and resuscitation and the impact this may have on the patient, their family and other staff. Ideally the prospect of such a scenario should be discussed with the family prior to any deterioration in the potential donor’s haemodynamic condition.

8.17 What if the tests reveal that the patient is dead and despite the patient’s express wish in life to become a donor, the family refuse to allow donation to take place until the heart has stopped? Should artificial respiratory support be removed and any donation take place by the DCD route?

8.17.1 Some families, even though they support organ donation, may find it difficult to agree to organs being retrieved until the patient’s heart has stopped beating. In some cases this may be because they cannot accept that death has occurred until the heart has stopped. In other situations families may accept the confirmation of death by neurological criteria, but may nevertheless feel an emotional need to witness the heart stop beating before they can accept the retrieval of organs.

8.17.2 Whilst DBD may result in improved quality for some organs, and better clinical outcome for the recipients of those organs, the needs of families should not be ignored.

8.17.2 Ultimately this is a matter for professional judgement at a time that is likely to be exceptionally stressful for the potential donor’s family. Families should be supported and given sufficient information about the options for donation. If the family cannot agree to retrieval before the heart stops beating, DCD might be acceptable to them and should be considered.
9. Potential and perceived conflicts of interest

9.1 In its guidance on DCD, UKDEC identified several areas where potential or apparent conflicts of interest might occur. That was because, for patients donating by the DCD route, several decisions and variations in treatment need to be made while they are still alive. DBD presents fewer challenges, because the timing of donation steps are different pressures are usually reduced as most, if not all, of the decisions and interventions can take place after the donor has been confirmed dead using neurological criteria.

9.2 It is imperative to ensure that all actions remain of overall benefit to the patient. Medical staff should act in accordance with the GMC Guidance on End of Life Care regarding organ donation.

9.3 The members of staff for whom real or perceived conflicts of interest are most likely to arise in DBD are Clinical Leads for Organ Donation (CLODs), Specialist Nurses for Organ Donation (SN-ODs) and Transplant Retrieval Surgeons. The risk here is that their designated role might seem to imply that securing successful donation could, for them, take precedence over other aspects of patient care. That must never be the case.

9.4 As CLODs are senior and experienced clinicians, usually based in ICUs and with teaching responsibilities, they are highly likely to be one of the ‘two medical practitioners registered for more than five years’ required, by the Academy Code of Practice, to conduct neurological tests to confirm death.

9.5 The Academy Code of Practice also states that ‘those carrying out the tests must not have, or be perceived to have, any clinical conflict of interest and neither doctor should be a member of the transplant team’.

9.6 CLODs should not be considered, simply by nature of their role, to have any specific conflict of interest in conducting neurological tests to confirm death or in facilitating DBD. Like any other health professional, CLODs have an overriding duty to ensure that the patient’s end of life care will be of overall benefit to them. The Academy Code of Practice provides a clear safeguard by ensuring that two senior and experienced clinicians carry out the confirmation of death and the CLOD can, and often will, act as one of the two clinicians. UKDEC is of the opinion that CLODs do not have a clinical conflict of interests as they are not members of the transplant team and have no role in the allocation of organs. Also, the CLOD is likely to have considerable knowledge and experience in this difficult area of medical practice and other healthcare professionals should avail themselves of this expertise when necessary.

9.7 The SN-OD’s liaison with, and support for, the potential donor’s family throughout the donation pathway is crucial.

9.8 UKDEC has recommended that prior to the confirmation of death, SN-ODs should not provide routine medical care for potential donors while they are still alive, to avoid any real or perceived conflict of interest. However, it is appropriate for the SN-OD to hold initial discussions about patients with the clinicians caring for them and to check the ODR status of a patient before death has been declared as this is an important part of the process that allows the assessment of steps that may be for the benefit of the patient.

9.9 After death, that potential conflict of interest no longer exists, and it is acceptable for a SN-OD to take care of the patient if necessary. The SN-OD will also continue to be the prime contact with the family. This may involve representing the concerns of a patient’s family to colleagues, especially the organ retrieval team (for example about cultural beliefs regarding the timing and manner of funeral arrangements). At times, such considerations may affect, or even prevent, the transplant process. The SN-OD’s primary obligation should be to the donor and their family, rather than to the transplant team.

9.10 Organ Retrieval Surgeons, and others with direct clinical responsibility for possible organ recipients, must not take part in the neurological tests to confirm death.
10. Conclusion

10.1 DBD as currently practised in the UK is ethically robust, and consistent with the principles established by UKDEC. Starting from the premise that testing to confirm death using neurological criteria in accordance with the Academy Code of Practice should be regarded as routine best practice in all appropriate patients, regardless of the possibility of donation, we have identified the ethical considerations relevant to a number of key decisions. These include decisions about undertaking such testing, interventions to facilitate donation, and caring for the patient.

10.2 We hope this document will help clinicians and others involved in donation and transplantation, especially those encountering these issues for the first time, by addressing and clarifying these issues.
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