Dignity in Donation

A one day ethics and law conference for healthcare professionals, policy-makers, lawyers, academics and others with an interest in organ donation.

Friday 27th April 2012
Nottingham Conference Centre
Nottingham Trent University
Sponsorship from Novartis

Novartis have kindly sponsored this event. Their support has, amongst other things, provided funds for this booklet of conference proceedings and for the conference fee of a number of the overseas speakers.

Other Acknowledgments

Thank you to the speakers for their contributions. Thank you also to Nottingham Trent University for hosting the event in such a splendid environment and to June Gorton and other members of its staff who have provided invaluable help with marketing and organisation.

Disclaimer

The views expressed in this booklet, the submitted abstracts and the conference proceedings should not be taken as endorsement from the conference organisers or sponsors. All views expressed are the individuals.

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This booklet should help you navigate to where you want to be at the appropriate times during the day.

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Page 24-27: Minority Report: Two secular positions opposing donation

The Cherry Blossom (front and back image)

The cherry blossom can mean sacrifice and the transient nature of life. Words that can be associated with organ and tissue donation.

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Welcome

Welcome to the conference. We think that many of the key ethical and legal issues in organ donation hinge to some degree on the issue of what dignity entails and whether or not it is something that should be regarded as imperative to protect. Hence, we thought that it would be an excellent idea to hold this conference.

Many of our speakers responded to our two calls for abstracts but a few were specifically invited to present on topics that would help round out the programme. 7 of our speakers have come from overseas (France, Italy x 2, Belgium, Latvia, Portugal, Germany) which has added considerably to the wealth of comparative material being presented.

We feel that an academic event such as this should air more or less the full spectrum of views and to support this end we have invited Carol Donaldson, a donor Mum, to present to the conference a personal message of what donation can mean to a family, and David Evans and David Hill, two retired clinicians, to present a critical secular view of organ procurement practices. Unfortunately David Evans and David Hill cannot attend in person but have presented their views to us and we have reproduced these in this booklet under the heading Minority Report.

We are planning to develop an edited collection based substantially on the material presented today with added contributions where appropriate. We will keep participants informed of developments on this front.

We hope you have an enjoyable and thought provoking day,


Tribute to Professor David Price

Many of you would have either known Professor David Price personally or known of his work. Sadly, David died over the Christmas/New Year period. David had an academic career of well over thirty years, most of it at the Law School of De Montfort University in Leicester. David built an outstanding international reputation through his work in the field of organ transplant law and ethics – contributing to numerous projects and official committees in the field as well as publishing extensively. I was one of David’s colleagues in the 1990s and he led the supervision of my PhD on the ethico-legal aspects of living organ donation. I have heard many people say what an excellent colleague and teacher he was and I would agree with these sentiments wholeheartedly. He focused on doing his work diligently and effectively. His genial and good hearted nature meant that helping students and others with gusto came easily to him. David was a great family man who was also very good fun to be around socially – taking a respectful and caring interest in the lives of others, sharing interesting anecdotes and stories and enjoying a good laugh and a joke. His funeral was attended by a large number of family, friends, colleagues and students – a tribute to the very high esteem in which he is held and a reflection of the fact that he will be sorely missed.

A lecture, in memory of David is being held on the 18th May at 6 pm in the Hugh Aston Building, De Montfort University, Leicester, followed by a drinks reception. The lecture is entitled ‘Palliative Care: an Ethical and Legal Duty?’ It will be given by the renowned medical law and ethics expert Professor John Keown, of Georgetown University, Washington, DC. All are welcome. To book a place please contact Kate Scott klscott@dmu.ac.uk, tel. 0116 207 8182.

Austen Garwood-Gowers
Conference Programme

9-9.30 Registration (Adams Room).

9.30-9.35 Welcome. Professor Andrea Nollent, Dean, Nottingham Law School, Nottingham Trent University (Adams Room).

9.35-11.00 Session 1 The nature of dignity and the case for/against its use in the organ donation context Chair Austen Garwood-Gowers (Adams Room)

9.35-9.45 Introduction to the nature of dignity, Austen Garwood-Gowers, Reader in Health Law and Ethics, Nottingham Law School, Nottingham Trent University

9.45-10.10 The use of dignity as a norm in health law, Myriam Cardinouche, LLM Student, Nottingham Law School, Nottingham Trent University

10.10-10.35 The case for preferring dignity over competing ethical approaches. Austen Garwood-Gowers, Reader in Health Law and Ethics, Nottingham Trent University

10.35-10.45 Chaired discussion and questions.

10.45-11.00 Drinks Break

11-12.50 Session 2 Death, dignity and donation Chair Dale Gardiner, Adams Room

11-11.25 A dignity consistent approach to defining and testing for death and the implications of this for cadaveric transplantation. Dale Gardiner, Midlands Clinical Lead for Organ Donation.

11.25-11.50 A donor family perspective, Carol Donaldson.

11.50-12.15 Intensive Care Attitudes to Deceased Donation, Helen Fenner Specialist Registrar in Anaesthesia, Nottingham University Hospitals, Charmaine Buss, Specialist Organ Donation Nurse, Nottingham University Hospitals and Dale Gardiner, Midlands Clinical Lead for Organ Donation.

12.15-12.40 Organ Procurement: A Case for Pluralism on the Definition of Death. Dr Kartina A Choong, Senior Lecturer in Medical Law, University of Central Lancashire.

12.40-12.50 Chaired discussion and questions.

12.50-1.50 Hot Lunch in the Old Chemistry Theatre.

1.50-3.15 Session 3 - Parallel sessions

A Pre death intervention Chair Anne-marie Duguet, Adams Room

1.50-2.15 Dignity as a pre-condition for pre-mortem interventions to facilitate organ donation. Jackie Brander, Team Manager, NHS Blood and Transplant, Midlands Organ Donation Services Team, Austen Garwood-Gowers, Reader in Health Law Nottingham Trent University and Dale Gardiner, Midlands Clinical lead for Organ Donation.

2.15-2.40 A Necessary Inhumanity? Can organ optimization be legally and ethically justified in potential organ donors? Collette Davidson, Bsc, final year medical student King’s College London School of Medicine.

2.40-3.05 Medical research before and after the death of the donor. Andrea Sautter, Doctoral Student, Institute for German, European and International Medical Law, Public Health Law and Bioethics (IMGB) of the Ruprecht-Karls-University of Heidelberg.

3.05-3.15 Questions and discussion
B. Dignity as priceless? Chair – Stefano Biondi, Hooley Room

1.50-2.15 Biotrust and dignity: A model for donations. Ilaria Colussi Ph. D. Candidate in Constitutional Law and Biolaw, 3rd Year of the Doctoral School of Comparative and European Legal Studies, University of Trento, Italy.

2.15-2.40 Dignity and Property on Bodily Parts: an irreconcilable antithesis? A comparative legal overview of the issue of bodily ownership and its implications on transplants. Stefano Biondi, Research Assistant, Department of Comparative Law, University of Florence, Adjunct Professor of European Law, New York University (Villa La Pietra campus), Florence, Italy, Attorney at Law, Florence Bar, Florence.

2.40-3.05 Dignity, property rights and the case for a futures market. Jane Langsdale, Public Governor, Public Governor, The Wirral University Teaching Hospital Foundation Trust.

3.05-3.15 Discussion and questions.

3.15.30 Drinks Break, Adams Room

3.30-4.55 Session 4: Parallels sessions

A. Dignity after death Chair Solvita Olsena, Adams Room

3.30-3.55 Dignity of deceased: Why to protect and how to protect? Solvita Olsena Dr.iur, MD, University of Latvia, Center of Biosafety and Bioethics, Riga, Latvia.

3.55-4.20 Respect of dignity of the body after death : the French protection. Anne-marie Duguet Senior lecturer, Inserm, Université de Toulouse III.


4.45-4.55 Questions and discussion

B. Dignity and protection in living donation Chair Sigrid Sterckx, Hooley Room

3.30-3.55 Safeguarding the dignity of living donors; the balance of risk and harm, Aaron Powell, Business Manager, Organ Donation and Transplantation at NHS Blood and Transplant (but speaking in a personal capacity).

3.55-4.20 Living organ procurement from mentally incompetents. K. Van Assche PhD student, Research Group Law Science Technology & Society (LSTS), Faculty of Law and Criminology, Free University of Brussels (VUB), Belgium and S. Sterckx Professor of Ethics, Bioethics Institute Ghent, Department of Philosophy & Moral Sciences, Ghent University, and Research Group Law Science Technology & Society (LSTS), Faculty of Law and Criminology, Free University of Brussels (VUB), Belgium

4.20-4.45 Any lessons to learn? Different Approaches to medical responsibility in three jurisdictions: Italy, Sweden and the UK: Comparative perspective drawing on organ donation case studies, Dr Katarzyna Gromek-Broc, York Law School.

4.45-4.55 Questions and discussion

4.55-5 Short break

Final Session

5-5.30 Has a case been made for dignity and if so what are its implications for organ donation? Brief analysis with speaker and participant interaction led by Austen Garwood-Gowers and Dale Gardiner.
A donor family perspective, Carol Donaldson, Donor Mum

James Donaldson is a hero...

Even after his death he has saved the lives of others through organ donation

Would You?
Join the NHS Organ Donor Register
tel: 0300 123 23 23
www.organdonation.nhs.uk
Abstracts for session 1 - The nature of dignity and the case for/against its use in the organ donation context – Chair Anne-marie Duguet

The nature of dignity, Austen Garwood-Gowers, Reader in Health Law and Ethics, Nottingham Law School, Nottingham Trent University

Dignity is often criticised as a vague concept that is consequently difficult to apply in practice. However, as well as giving a basic feel for what it means this introduction 'locates it' by identifying its relationships with key values in the health field such as identity, equality, non-commodification and integrity, protection of wellbeing and autonomy.

Dignity as a norm in health law Myriam Cardinouche, LLM Student, Nottingham Law School, Nottingham Trent University and Austen Garwood-Gowers, Reader in Health Law and Ethics, Nottingham Law School, Nottingham Trent University

Law affecting the health field is largely a mixture of protections of bodily integrity, other protections of personal rights (such as through the law of confidentiality) and provision for access to medicine. Dignity is not only an implicit basis for all of these protections but sometimes also an explicit one. For example, it is a key driver not only within human rights instruments that are general in nature but also those which are specific to the health field – such as the Convention on Human Rights and Biomedicine 1997 and Universal Declaration of Bioethics and Human Rights. Indeed, this paper will argue that it is not overstating matters to consider protecting dignity to be a moral, political and often even legal obligation.

The case for preferring dignity over competing approaches Austen Garwood-Gowers, Reader in Health Law and Ethics, Nottingham Trent University

Philosophical theories can be divided into those that attempt to ground themselves on respect for human beings as ends and those that do not. This paper will not only argue against the use of the latter both generally and in the health field. It will also stress that the former need to be compatible with dignity in order to successfully ground themselves on respect. Throughout the paper exemplars from, and applications to, the field of organ donation will be provided – though only in broad outline in order not to steal the thunder of subsequent speakers and the synthesising lecture/interaction at the end of the day!
Abstracts for session 2 - Death, dignity and donation Chair Dale Gardiner

A dignity consistent approach to defining and testing for death and the implications of this for cadaveric transplantation. Dr Dale Gardiner, Adult Intensive Care Consultant Nottingham, Midlands Clinical Lead for Organ Donation.

‘Have me decently buried, but do not let my body be put into a vault in less than two days after I am dead.’

Alleged dying request of George Washington, 1799.

A dignity consistent approach to cadaveric transplantation depends on adherence to the Dead Donor Rule. At its simplest the Dead Donor Rule states that donors must be declared dead before their organs are taken, and was coined by John Robertson in 1988, but was well recognised by the Judicial Council of the American Medical Association writing in 1969.

An attitude expressed against transplantation, is that the definition of death and the criteria used to confirm death, has been altered over time for the purpose of benefiting transplantation. If the donors are not dead at the time of donation, or if their diagnosis of death is somehow, inferior, to the same diagnosis in non-donors, for reasons of maximising benefit to the transplant recipient, than the Dead Donor Rule may be being breached.

Dying, however, is a process, which affects different functions and cells of the body at different rates of decay. The diagnosis of death is, in most countries, the legal responsibility of a medical practitioner. Doctors must decide at what moment along this process there is permanence and death can be appropriately declared. This moment is a balance between safety, those declared dead must stay dead, and timeliness, the declaration of death should not be unnecessarily delayed.

Humans have long used criteria and technology to assist in the diagnosis of death. The history of these criteria more closely parallels the history of resuscitation and advances in medical investigations, rather than the history of transplantation (see Table 1).

Current standards for diagnosing human death, regardless of donation potential, use criteria that are international, ethically substantial, and supported by sound scientific and physiological rationale. Our understanding and the criteria used may have evolved, but the duty remains the same, to make a timely diagnosis of death whilst avoiding any diagnostic errors; an obligation medical professionals cannot and should not abdicate.

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1 Arnold RM, Youngner SJ. The dead donor rule: should we stretch it, bend it, or abandon it? Kennedy Inst Ethics J 1993; 3: 263–78.
3 Footnote 1.
### Table 1. A Comparative History of Developments in Resuscitation and Medical Investigations, Diagnostic Criteria for Death, and Transplantation.

<table>
<thead>
<tr>
<th>Timeline</th>
<th>History of Resuscitation and Medical Investigations</th>
<th>History of Diagnosing Death</th>
<th>History of Transplantation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre History</td>
<td>Somatic criteria, such as the presence of decomposition and rigor mortis, are the oldest in human history but persist, even as the primary diagnostic criteria for death, up until the late 19th Century.</td>
<td>The link between breath and life is found in both Genesis (2:7) and the Qur’an (32:9).</td>
<td></td>
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<tr>
<td>Ancient History</td>
<td>The first recorded attempt at mouth to mouth resuscitation was by Elisha around 800 BC (2 Kings 4:34), &quot;...And he went up, and lay upon the child, and put his mouth upon his mouth… and the flesh of the child waxed warm.&quot;</td>
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<td>12th Century</td>
<td>Rabbi and physician scholar Moses Maimonides, was the first to argue that a decapitated person was immediately dead, despite the presence of residual movement in the body.</td>
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<tr>
<td>17th – 18th Century</td>
<td>Shakespeare writes of King Lear requesting a looking glass, 'If that her breath will mist or stain the stone, why then she lives.' (King Lear Act V Scene III). Feathers and candles were often utilized for a similar purpose.</td>
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</tbody>
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5 Taken from [http://www.ukdivers.net/history/cpr.htm](http://www.ukdivers.net/history/cpr.htm) and other sources.
7 [http://www.blood.co.uk/about-blood/history/](http://www.blood.co.uk/about-blood/history/)
<p>| 19th Century | 1819, Rene´ Laennec invents the stethoscope. | 1846 Paris, Dr Eugene Bouchut wins the Academy of Sciences prize for the best work on the signs of death and the means of preventing premature burials. He advocates the use of the stethoscope, as a technological aid to diagnose death. Bouchut believed that if a heartbeat was absent for 2 minutes, a person could be considered dead. In the face of opposition, he extended the period to 5 minutes. | 1818, Dr James Blundell conducts transfusions in cases of haemorrhage after childbirth. |
| Early 20th Century | Harvey Cushing describes increased brain pressure provoking respiratory arrest with preserved heartbeat. | 1902, Ulmann reports the first renal autotransplantation in a dog (grafting a kidney into the neck). | 1905, First reported cornea transplant in Moravia (now Czech Republic) |
| 1927, Moniz develops cerebral angiography, a technique allowing blood vessels in and around the brain to be visualised. | 1929, Electroencephalogram (EEG) discovered | 1906, First xeno-transplantation in humans, unsuccessful. | 1918, Human blood transfusion becomes a reality. |</p>
<table>
<thead>
<tr>
<th>Time Period</th>
<th>Event</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Mid 20th Century</td>
<td>A definition of death is proposed as a drop in brain electric potentials and the EEG is used to show loss of brain potentials after ischaemia. Proposed that death may be due to cessation of cerebral blood flow.</td>
<td>1933, First kidney transplant from cadaveric donor, unsuccessful.</td>
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<tr>
<td>1940s</td>
<td>Danish medical students hand ventilate polio victims during epidemic.</td>
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<tr>
<td>1950s</td>
<td>Mouth to Mouth resuscitation begins to gain prominence. Mechanical ventilation becomes possible and intensive care practice begins. Cerebral circulatory arrest is demonstrated in comatose patients by angiography. Doctors discover empirical proof to the concept of neurological criteria for death (brain death), by the identification of mechanically ventilated patients in coma dépassé.</td>
<td>First successful kidney transplant between identical twins.</td>
</tr>
<tr>
<td>1960s</td>
<td>Dr Kowenhoven introduces closed chest massage (cardiac massage). The crucial aspect of this technique is that the patient receives oxygen, which is transported to the brain by the development of a minimal blood circulation. On this basis many national and international guidelines to perform CPR are published. Proposed that the EEG can demonstrate death of the Central Nervous System. 1969, Ad Hoc Committee of the Harvard medical School define irreversible coma as a new criterion for death and provide clinical criteria to confirm death using neurological criteria.</td>
<td>1962, First successful kidney transplant from a cadaveric donor following cardio-respiratory arrest. 1963, First successful liver and lung transplant from a cadaveric donor. First successful organ transplant from a brain-dead donor. 1966, First successful pancreas transplant from a cadaveric donor. 1968, First successful heart transplant from a cadaveric donor who met criteria for brain death but was allowed to proceed to cardio-respiratory arrest prior to donation.</td>
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<td>Century</td>
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<td>Organ donation from 'brain dead' donors increases worldwide. The majority of donors come from intensive care units.</td>
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<tr>
<td>21st Century</td>
<td>Growing use of extracorporeal membrane oxygenation and other techniques to support the circulation, establish that it is possible to be alive, without a heart-beat.</td>
<td>2008, UK publishes new guidelines for diagnosing death, that for the first time give guidance for diagnosing death after cardio-respiratory arrest. 5 minutes is proposed as a minimum observation time after cardio-respiratory arrest provided no resuscitative efforts are commenced. Considerable variation in this time exists internationally (2 – 20 minutes)</td>
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<td>Growing gap between the number of donors and those on the transplant waiting list leads to the reintroduction of donation from those declared dead after cardio-respiratory arrest.</td>
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<td>2010, growing international medical consensus that all human death is anatomically located to the brain.</td>
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**Intensive Care Attitudes to Deceased Donation, Helen Fenner Specialist Registrar in Anaesthesia, Nottingham University Hospitals, Charmaine Buss, Specialist Organ Donation Nurse, Nottingham University Hospitals and Dale Gardiner, Midlands Clinical Lead for Organ Donation.**

**Background:**
Despite controlled donation after circulatory death (DCD) accounting for more than 30% of all deceased organ donation in the UK and having had a ten-fold increase over the last decade¹, many intensive care staff harbour negative emotions toward this 'new' form of organ donation. We wanted to explore the emotions behind DCD in an effort to more fully understand the strength of feeling in intensive care staff and by exploration, attempt to change attitudes and promote a more positive appreciation of DCD.

**Method:**
At the Mid Trent Critical Care Network (MTCCN) Annual Conference held on the 7th November 2011, a workshop was run by the authors, exploring emotions and attitudes in intensive care staff on deceased donation. Participants at the workshop were asked in small groups to write down words they associated with donation after brain death (DBD) and DCD. A briefing at the beginning created a safe environment in which people could freely use any word they wanted and group posters were created and discussed within the workshop. The words were chosen to have either positive or negative associations to donation by three blinded individuals: a lawyer with an interest in medical ethics, a hospital communications manager and a final year medical student.

**Results:**
The MTCCN has been in existence since April 2000 and consists of eight adult critical care units, across five different trusts. 108 participants, a mixture of critical care doctors, nurses and allied health care staff attended the annual conference. 69% were female, 31% male. In total, 22% of participants were doctors.

The numbers of positive words associated with DCD was 29, compared with 89 negative words. Examples of frequent words include: Life saving, hopeful, valuable and a good idea, whereas negative examples include: Barbaric, traumatic, body snatching and horrific. The opposite was found when looking at DBD; the number of positive words was 68 versus 25 associated with negativity. Examples of positive words include: Organised, planned, dignified and controlled. Examples of negatives include: Drawn out, suicide, time consuming and distressing. The difference between DBD and DCD was statistically significant (p<0.001), and remained significant (p<0.001) even after all words that did not have unanimity between the three blinded observers, were excluded. More words achieved unanimity between observers in DCD compared to DBD (p<0.001).

**Discussion:**
At the conference we were able to discuss some of the emotions that DCD evokes. Those who seek to promote DCD in UK hospitals forget the strength of these emotions at their peril. By completing this workshop we have found that there are many negative and emotive words associated with DCD that through discussion and information we can try to promote organ donation. Hopefully, by addressing the opinions of health care professionals that are involved in end of life care and organ donation we can dispel any myths, reduce stigma and try to improve team dynamics and attitudes towards organ donation. The NHS must start to embrace organ donation as a usual and not an unusual event.

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Brain stem death has, since the 1970s, been accepted by the medical fraternity in the UK as the means for defining death. Its subsequent endorsement by the courts now makes it lawful for the treatment of a patient who have been diagnosed and certified as brain stem dead to be terminated and for his organs, particularly vital organs, to be removed for transplantation. However, this definition of human death has never been universally accepted. Muslims, Orthodox Jews and Roman Catholics for instance, associate death with the departure of the soul from the body.

This crucial moment is usually linked more to respiration rather than brain activity. For them, terminating a life-support machine upon the pronouncement of brain stem death would therefore be tantamount to murder. Likewise, Buddhists and Hindus believe that the mind and body are integrated. Hence even where a patient is brain stem dead, his spirit and consciousness still lingered if his heart is still beating. The removal of life-support would therefore be akin to killing the patient. For the adherents of these faith traditions at least, brain stem death may not equate absolute death. Yet this criterion has been and continues to be the sole definition used across ICUs in Britain to ascertain death.

This paper seeks to argue that this definition of human death should not be superimposed upon patients who subscribe to different ideas of when death takes place. Rather, it puts forward the view that English law should facilitate and protect patients’ right to choose which concept of human death they would like to be applied to their deaths. In an increasingly multi-religious and multi-cultural society, this would safeguard patients’ autonomy and dignity far more that the current ‘one size fits all’ paradigm. This could in turn lead to an increase in the number of people willing to donate their organs when they die.

References:
- Bedir, A. & Aksoy, S., ‘Brain death revisited: it is not “complete death” according to Islamic sources’ (2011) 37 Journal of Medical Ethics 290.
- Re A (a minor), (1992) 3 Medical Law Reports 303.
Abstracts for Session 3A - Pre death intervention Chair Anne-marie Duguet

Dignity as a pre-condition for pre-mortem interventions to facilitate organ donation. Jackie Brander, Team Manager Midlands Organ Donation Services Team, NHS Blood and Transplant, Austen Garwood-Gowers, Reader in Health Law and Ethics, Nottingham Trent University and Dale Gardiner, Adult Intensive Care Consultant Nottingham University Hospitals, Midlands Clinical lead for Organ Donation.

Donation after Circulatory Death (DCD) is a way to increase the donor pool. The practice itself is not new but with advances in medical technology and a worldwide shortage of organs for transplantation, there is a potential for boundaries to be pushed. One of the implications of dignity in this context is that people should be able to make informed choices about medical interventions that they might be subject to, not only contemporaneously but in advance. Indeed, this policy is generally reflected in the broad legal acceptance of advance decision-making evident in many national laws - particularly within Europe and including specifically England and Wales. Encouraging active respect for dignity raises the question of whether the possibility and potential effects of pre-death interventions to preserve the quality of the organs for transplantation should be disclosed to those who are considering donation after death before they 'sign up,' enabling them to make informed choices about these should they wish to do so.

This paper considers pre-mortem interventions in this context. It also defends the use of the best interests test in circumstances where such advance choice has not been made and explores the potential implications of that test. It will critically consider whether existing practices are consistent with best interests and with ethico-legal standards as a whole and subject potential practices (such as elective ventilation which was recently re-considered by the British Medical Association) to the same scrutiny.

A Necessary Inhumanity? Can organ optimization be legally and ethically justified in potential organ donors? Collette Davidson, Bsc, final year medical student King's College London School of Medicine.

Annually the number of patients requiring organ donation increases while supply remains relatively stable. Most donors are declared dead as a result of brain death (heart beating donors), however, many patients who are declared dead because their heart stops beating (non-heart beating donors). Cardiac death results in physiological changes which can make the organs unsuitable for transplantation. In some cases these changes can be predicted and minimized by interventions performed on the patient pre-mortem aimed at optimizing organ function. These interventions confer no medical benefit for the patient but are done for the benefit of future recipients of donated organs. This paper looks at whether the interests of society to maximize the number of available organs, legally and ethically, justifies organ optimization. Specifically this paper considers the impact such a policy would have on the dignity of the dying patient: the potential donor.

Firstly the link between autonomy and the dignity of the donor is explored. One way patients protect their dignity is through autonomous, informed decisions. Examining the information available about organ donation suggests the public are not well enough informed to consent to organ optimization. Information could be provided to the public to facilitate informed consent. Some people may want these interventions to facilitate donation. This choice could be regarded as an expression of their narrative. Failure to carry out organ optimization could be regarded as ignoring the patient's dignity. This would have to be justified.

10 Mental Capacity Act 2005 (Sections 24-26).
The second issue considered is the legal best interests test. Most patients will not articulate their opinions about organ donation, and in particular organ optimization as they are unlikely to be aware of that possibility. At the time organ optimization takes place the person lacks capacity and so, medical decisions are made in the patient’s best interests. The best interests test provides a way to protect the dignity of the patient. This paper explores whether organ optimization goes beyond to scope of the best interests test. The analogy of medical research with patients who lack capacity might provide a way to abandon the best interests test while preserving the donor’s dignity.

In the public discourse about the need for organs it is easy for the donor’s ‘voice’ to get lost. However, these patients, and their families, give a special gift to society. It is important that society’s search for organs should not lead to blindly adopting a policy of organ optimization at the price of the individual’s dignity.

Medical research before and after the death of the donor. Andrea Sautter, Doctoral Student, Institute for German, European and International Medical Law, Public Health Law and Bioethics (IMGB) of the Ruprecht-Karls-University of Heidelberg.

A standard medical treatment always needs to be improved by constant research; this also applies to organ transplantation. However, medical research on the donor in the interest of later carrying out organ donation is problematic.

Medical research on a living person principally requires an informed consent. When the donor is unconscious, consent can only be presumed. Measures which only serve the interests of a third party conflict with the donors’ dignity. Can measures which are not harmful to the donor be justified? The crucial question is how to determine the point in time when a patient can be eligible for taking part in a study for improving the process of organ donation research.

The justifiability of research on the donor after the announcement of death can result from an informed consent of the donor, an informed consent of his relatives or from prevailing interests of the community. But, in the majority of cases, an informed consent of the donor does not exist. The reason for the unwillingness of people to register as a donor may be the way, organ donation is promoted. In most cases, the promotion mainly concentrates on the positive effects for the recipient, instead of emphasizing the positive aspects for the donor, such as the right of self-determination of one’s own body and the relief for the relatives that arises from a decision made by the potential donor himself.

In the request process to obtain family consent for organ donation, the question if the necessary medical research may be performed may provoke a refusal both of the research and the donation itself. So the researcher very often has to go back to a justification by community interest. Medical research cannot be justified by the interest of an individual recipient, as the research is not necessary to serve his interests. Research methods can only be justified with prevailing interests of the community on condition that there are no contradictory interests of the donor. Such contradictory interests will be assumed if harmful methods are used. You can classify methods as harmful, which require prolongation of the donor’s cardiovascular system or which lead to a further defacement of his body.
Session 3B – Dignity as Priceless?

Biotrust and dignity: A model for donations. Ilaria Colussi Ph. D. Candidate in Constitutional Law and Biolaw, 3rd Year of the Doctoral School of Comparative and European Legal Studies, University of Trento, Italy

This paper reflects upon the applicability and function of human dignity within the context of donation by starting from the example of research tissue “biobanks” (organized collections of human tissues, used for research purposes). Looking at the issue of the status of body and body parts within a biobank, i.e. the relationship that the individual can establish with his/her body (and components of it), the work considers the two main positions in the field: one applying the property model to human tissues and the other considering them as “commons”. Both the positions appeal to the concept of human dignity in opposite ways. The model that recognizes property rights upon human body uses dignity to affirm that the lack of recognizing property rights to individuals upon their bodies would be a violation of human dignity; the other position, on the contrary, states that assigning a value of chattel to human body is an infringement of human dignity.

In order to solve the ambiguity derived by the application of the same concept of human dignity to support two opposite positions, the work makes reference to the solution offered by some authors12 that have elaborated the framework of “biotrust” to explain the relationship between a human being and his/her body. In this framework, each human being is seen as a “settlor” of his/her body, having a role of “custodianship” or “stewardship” towards his/her body. Here, human tissues are neither object of property nor commodities, but sources of benefits for the community.

Analogously, in the case of donation where the main subjects are usually a donor, intended as an active subject, and a recipient of such a donation, the property model or the model of commons is not appropriate. Instead, the donor should be conceived as a settlor or custodian of his/her body, thus the notion of human dignity could show itself in its two dimensions: the individual (by the side of the donor that is never treated as a means) and collective one (by the side of the possible recipients that could benefit of such a donation, recipients that are recognised in their human value and as belonging to humanity).

In conclusion, the work takes the example of biobanks to verify how the concept of human dignity could have a meaningful role in the context of donations, both in the individual and collective facet.

Dignity, property rights and the case for a futures market Jane Langsdale, Public Governor, Public Governor, The Wirral University Teaching Hospital Foundation Trust.

There is an entrenched idea in the minds of many that there are limits as to what should be bought and sold as commodities. Some things are so valuable, priceless or sacred, that they should never be offered in the market place. Selling human organs offends against common notions of decency and is, understandably, equated with a violation of bodily integrity and commercializing our humanness. By subjecting the body and its parts to the dictates of a market, we are losing our moral compass by allowing markets into areas where they have no place: there being a perceived sentiment that we are diminished as human beings and our sense of dignity lost.

However, as evidence shows that more and more people are prepared to turn to the 'black market' to secure life saving human organs and tissue, in this paper I shall explore the controversial possibility of setting up a highly regulated commercial market in organs and tissue.

Currently commercial transactions in organs and tissue are prohibited under statute. This is broadly based on social precepts that prohibit perceptions of humans as commodities to be traded. I shall argue for a reappraisal of property rights as they apply to the human body. Legislation does reflect certain contradictions in the commodification debate by allowing certain human material to be bought and sold but not others. I will also consider the concept of dignity in this context. I will ask the question: ‘do we really want to address the increasing demand for organs and tissue by simply allowing underground systems to flourish?’ and positing the idea that there is no dignity either in transplant tourism or in allowing the shortage of organs and tissue worldwide to be met by illegal traffickers.

Dignity and Property on Bodily Parts: an irreconcilable antithesis? A comparative legal overview of the issue of bodily ownership and its implications on transplants. Stefano Biondi, Ph.D. in Comparative Law, University of Florence, Italy, Research Assistant, Department of Comparative Law, University of Florence, Italy, Adjunct Professor of European Law, New York University (Villa La Pietra campus), Florence, Italy, Attorney at Law, Florence Bar, Florence, Italy

The Nice Charter of Rights, just as several Continental European Constitutions, provides that human dignity is inviolable. This statement is regarded by many Continental European legal scholars as incompatible with a proprietary relation between individuals and bodily materials. This approach has partly been endorsed by the ECJ in the recent Bruestle-Greenpeace case. But are property rights over the body really in contrast with dignity?

This assumption, so strong in Continental Europe, can partly be attributed to the conception of the right to property existing in Civil Law legal systems, which places a greater emphasis on the absolute nature of proprietary rights than Common Law legal systems. This notwithstanding, denying the existence of this property relation leads to contradictory conclusions and sometimes to an inadequate protection of individual interests.

This paper will attempt to show that that focusing on an appropriate legal recognition and protection of individual dignity rather than on the issue of the legal status of the human body and bodily parts is more helpful in assessing the adequacy of the regulatory framework of transplantation in a given jurisdiction. Particular attention will be dedicated to living donor transplants.

The paper will briefly outline the main differences between the common law and the civil law idea of property; it will then describe the status quo of legal debates on the issue of bodily ownership in selected Civil Law jurisdictions of Continental Europe (particularly France and Italy), taking into account the common supranational framework (EU and Council of Europe); it will subsequently describe how positive legal sources and courts interpret the concept of “dignity” and how such concept is applied in the context of transplantations; and it will conclude with some comparative legal remarks about what lessons could be learnt from the experience of the legal systems that have been considered.
The protection of human dignity is established in the 95th Article of the Latvian Constitution - Satversme. "From the Constitutional provision, it is clear that the Constitution imposes the obligation on the state and national power to protect human dignity and honour, to take all necessary measures to ensure the dignity and honour, and protect those values in case of violation. It should be noted that this article contains a mandatory order to protect."

Looking at protection of human dignity in the context of various medical manipulations, the unique value of a human being as well as the dangers of human instrumentalization is always emphasized. The above mentioned is also stressed by the German Federal Constitutional Court (GFCC): "The State violates human dignity when it treats persons as mere objects. It is contrary to human dignity to make persons the mere objects in the state or 'of the State.'" The GFCC has clearly explained the need for protection of human dignity after death. In the ruling on the protection of a deceased person's dignity in the so-called Mefisto case, the GFCC determined: "It would not be compatible with the protection of human dignity, who is entitled to dignity according to his own existence, would be deprived of the dignity after death or that he could be humiliated. [...] The imposed obligation to the entire state power to guarantee protection against attacks on human dignity does not end with the death of a person."

Both historically reinforced protection system of a deceased person as well as the knowledge of modern legal theory suggest that the fundamental human rights, especially dignity as the basic value of fundamental rights, works more widely, not only during the period from birth to death. The development of medicine in the field of dead human tissue utilization has been very fast, but the legal system has failed to adequately and to the necessary extent to respond to the on-going practice. Therefore it is necessary to discuss dignity protection requirements in deceased donation processes. For practical implementation of dignity protection it is important to know how to protect dignity of deceased.

**Respect of the dignity of the dead body**

After death the memory of the person is honored, moreover, the image of the deceased is being protected: The publication in a newspaper of photographs showing the remains of corpses in a mass disaster has been characterized by the Court as a violation of human dignity.

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16 Law 2008-1350 on funeral legislation
dignity. Peace due to the dead bodies is not satisfied when, during an exhumation, the remains of a person of Muslim faith are placed, by mistake, into a mass grave with those of people of other faiths. The Court recognized that the mortal remains are object of respect, whose sanctity is recalled in Article 16-1 of the Civil Code.

**Exhibition of Dead Bodies**

Public paid exhibitions of real human bodies have been presented in the World (15 million visitors says the advertising of "Bodies The exhibition"). The respect of the human body remains after death in all the cultures. The bodies presented in the exhibitions were supposed to come from China. In France when the exhibition arrived in Paris (after Marseilles and Lyon), two associations acting for solidarity with China claimed in justice to close the exhibition. The judge followed their request on the basis of the article 16-1-1 of the Civil Code for violation of the dignity of the body, and the exhibition has been forbidden.


**Introduction**
Strategies to achieve an increase in organ donation include the expansion of donation after controlled or uncontrolled cardiac death (cDCD, uDCD), an opt-out system and financial incentives to families of donors. Uncontrolled organ donation is routine in some European countries but not the United Kingdom. The aim of this project was to canvass opinion regarding these strategies with a focus upon uDCD.

**Methods**
Over one weekend the public were approached in two areas of Birmingham (central and suburban shopping areas). Those willing to participate were sent an email with a link to an online questionnaire. Scenarios describing donation after brain death (DBD), cDCD and uDCD were provided. The thoughts towards consent and placing perfusion catheters in uDCD prior to consent were specifically sought.

**Results**
The response rate was 63% (295/472). 31% would probably and 50% definitely support a switch to an-opt out system. 69, 70 and 74% would consent to the donation of a loved one’s organs after DBD, cDCD and uDCD. If this person was on the organ donor register 93% of those initially declining donation would give consent. 85% thought that placing catheters for uDCD without family consent should occur; if the potential donor was on the organ donor register this figure increased to 94%. 41% would probably and 45% definitely support the introduction of uDCD to the UK. However, 14% thought that carrying a donor card would negatively influence resuscitation efforts in the event of cardiac arrest. 65% did not agree with financial compensation to families of organ donors.

**Conclusions**
The introduction of an opt-out system to the UK would be supported by the public as would uDCD. Consent rates for donation after uDCD would be equivalent to, if not higher than, DBD and cDCD. Concerns regarding placement of perfusion catheters without specific consent were not widely expressed and would be largely negated if the person was on the organ donor register.

17 Crash of the cable car of Pic de Bure the Journal Paris Match has been sanctioned with 12 000 euros for compensation by the Court of Nanterre Libération 27/02/03
18 TGI de Lille 10 nov 2004
19 CA Paris 30 avril 2009 n° 09/09315 Jurisdata n° 2009-002649
Safeguarding the dignity of living donors: the balance of risk and harm, Aaron Powell, Business Manager, Organ Donation and Transplantation at NHS Blood and Transplant (but speaking in a personal capacity).

Living organ donation is increasingly recognised as a means to address the perceived shortage in the number of available organs for transplant from deceased organ donors. In some cases, particularly kidney transplantation, organs from living donors provide more favourable transplant outcomes and longer graft survival rates. It is therefore unsurprising that strategies to promote living organ donation and expand the pool of living donors are being adopted by transplant organisations in various countries.

In these circumstances, the protections afforded those who become, or who are asked to consider becoming, living organ donors, become a matter of ethical and potentially legal concern. This paper therefore provides a brief overview of the medical risks associated with different types of living organ donation before identifying the various mechanisms currently being used to expand the available pool of living donors. Consideration is then given to the protections currently in place, primarily in the United Kingdom, to protect living donors in a number of areas including, but not limited to, the medical risks identified.

Attention will be paid to the extent to which living donors are made aware of the risks involved in donation; the safeguards provided for their future medical needs including the state of knowledge of such needs and long term follow-up data; as well as the psychological health of donors and protections from inappropriate pressure to donate. It should be noted that consideration is given in this paper to capable adult living donors: the ethical and legal issues associated with incapable donors is considered in another paper to be presented at this conference.

Living organ procurement from mentally incompetents. K. Van Assche PhD student, Research Group Law Science Technology & Society (LSTS), Faculty of Law and Criminology, Free University of Brussels (VUB), Belgium and S. Sterckx Professor of Ethics, Bioethics Institute Ghent, Department of Philosophy & Moral Sciences, Ghent University, and Research Group Law Science Technology & Society (LSTS), Faculty of Law and Criminology, Free University of Brussels (VUB), Belgium

Confronted with a growing demand for organ transplants and an inadequate supply of cadaveric organs, transplant centres and desperate patients have increasingly looked to living donors. In a further effort to address organ scarcity, various strategies to enlarge the pool of living donors are currently being examined, including relaxing the principle of non-commercialisation, adopting new allocation models, and extending criteria for acceptance of organs. Continuing liberalisation of living donor criteria may even result in mentally incompetents being considered as an additional source of organs. However, since mentally incompetents are incapable of giving free and informed consent, their use as living donors is bound to raise serious ethical issues.

This problem may be especially pressing in countries like Belgium, where transplantation regulations are very lenient with regard to the use of mentally incompetents as organ donors. With the case of Belgium as a negative example, this presentation will evaluate the legitimacy of using mentally incompetents as organ sources. First, we examine the underlying moral dilemma that results from the necessity of balancing the principle of respect for persons with the obligation to help people in desperate need. Second, we look at various legal solutions that have been proposed to address this dilemma, ranging from a categorical prohibition to a very permissive approach. By way of illustration, we provide a comparative overview of the regulation in 20 European countries and the United States. Finally, we discuss the main requirements that have been put forward in countries where organ removal from incompetent donors is legally allowed.
Any lessons to learn? Different Approaches to medical responsibility in three jurisdictions: Italy, Sweden and the UK: Comparative perspective drawing on organ donation case studies, Dr Katarzyna Gromek-Broc, York Law School.

The paper will start with the theoretical inquiry how various jurisdictions approach the question of responsibility for outcomes in medical cases and what role the principle of fault plays in assigning or attributing responsibility for an outcome. Some case studies from the organ donation field will be explored. It will look at how the notion of moral responsibility can be used to account for the distinction between justifications and excuses. How relevant is a notion of causation in medical cases in the examined systems and how does it impact on the victim's redress? How do other regimes approach the question of acts and omissions? (Hart and Honoré argument versus Hogan). Is the issue of establishing of responsibility a fundamental value in restoring dignity of the victim? What are other more effective ways and mechanisms that would improve the system of redress in the UK and put the victims' interests in the centre? What lessons could we learn from this comparative study? Could we be inspired by the Swedish example?

Final Session,
Has a case been made for dignity and if so what are its implications for organ donation? Brief analysis with speaker and participant interaction led by Austen Garwood-Gowers and Dale Gardiner.

The final session will integrate the day together by exploring and inviting participants contributions on the topics of whether dignity is an appropriate ethico-legal driver for organ donation, what its implications are for organ donation in general (for example, vis-à-vis notions of limits to medicine, competing demands for resources, prevention and other therapeutic options) and what its implications are across specific areas (especially approach to death, pre-mortem and post-mortem intervention, living donation and commodification)

Additional Abstracts Received From Experts Who Were Unable to Attend:


The use of human tissue has been central to medicine for almost as old as medical practice itself; ranging from experimentation for increasing understanding of the anatomy and physiology of the body consequential to development of therapeutic interventions, to direct use as therapeutic interventions such as transplantation. Today biomedical research such as genetic studies and drugs development that has revolutionised medicine evolved from the use of human tissue from cellular to organ level. For example, organ transplantation, a fast growing procedure has made significant impact on life expectancy and quality of life to millions of people across the world. However, the use of human tissue evolved through involuntary and inhumane practices, the climax of which resulted in an outcry for regulation to inculcate sanity and dignity.

Central to regulation has been the evolution of medical law and ethics. Consequently, in most civilised societies today, the use of human tissue, dead or life, is voluntary following well informed consent. While this is the positive result of regulatory measures that has empowered the individual, it has been to the imbalance of community interests on what happens to his body. Organ transplantation, for example, although in general the number of donors in UK has increased over the years, has not matched that of recipients at any time. This could partly be the result of increasing awareness of the individual of his rights and dignity of his body consequently its disposal, regardless of his community’s interests. It looks from this the same legal system that brought sanity to the use of human tissue is lopsided in favour for the individual than other stakeholders, not the least his community.
To bridge the gap calls for consortia approach fulcrum on all stakeholders’ interests. This paper examines the various stakeholders in facilitating dignity in organ donation consequential to enhancing numbers. It looks at the need for organ donation; current rates of organ donation in UK; the body and its stakeholders: the donor – dignity of ownership and giving, public interest – dignity of receiving and facilitating giving; the respective roles of the government, and medical law and ethics in enhancing organ donation; finally conclusion calling on the UK regulatory legal system to keep in pace with development in transplantation in particular, and the use of human tissue in medicine in general, both nationally and globally.

**Consent for transplantation and for Biobanking – Two sides of the same coin? Rafael Vale e Reis, Assistant Professor, Faculty of Law, Coimbra, Portugal, University of Coimbra, Portugal/Researcher, Biomedical Law Centre of the Faculty of Law, Coimbra, Portugal.**

In Portugal, even before the Directive 2004/23/EC, was already enacted a law on the collection and transplantation of organs, tissue and cells of human origin - Law no. 12/93, of 22 April. After the Directive, Law no. 22/2007, of 29 June wrought some changes in Law no. 12/93, of 22 April, in order to harmonize national legislation with it. Regardless those legal changes, the Portuguese legal model for transplantation of organs remains the **opting out model**. For biobanking, Law no. 12/2005 establishes that, for the procurement of a biological sample, consent must have written form, and the information provided and written must cover the purposes of the biobank, kinds of research to be developed, its potentials risks and benefits, conditions and time of storage, measures that are being taken to protect privacy and confidentiality of involving the participants and what researchers intended to do regarding the communications (or lack of it) on results obtained with the biological material collected (Article 19, no. 5).

This legal solution may be interpreted as requiring a specific informed consent, and thus forbidding broad consent from the subject who contributes for the creation of a biobank. One should question if this different legal approach for the “donation” of body parts has its (ethical, practical, philosophical) grounds or if it is just a gap, derived from the innovation brought by biobanks.

On this presentation, we will try to discuss whether we should keep these differences and be prepared to change the views on informed consent for biobanking, and if so what are the practical end theoretical consequences. Some questions arise: Why does the law provide so many different solutions for the human body? Is it relevant for the best legal solutions the fact that we are discarding parts from a deceased person? Which rights can relatives claim in this field?
Dear Delegates,

Thank you very much for the kind invitation [to present at the Dignity in Donation Day] which, perceived as an unique opportunity to present uncomfortable facts to an open-minded audience, I would have been delighted to accept 10 years ago – or even 5 years ago, perhaps, after losing a battle with my conscience which compels me still to do whatever I can to make the relevant facts about organ procurement widely known. However, I must reluctantly accept that I am now too old. In declining, I venture to hope that my opposition to human organ transplantation – a position reached, with even greater reluctance, after almost 40 years of intense consideration – might be made known to those attending your conference in some way. In brief and quotable form it can be stated thus :-

**Human organ transplantation is Wrong because it necessitates the abuse of the dying or harming the healthy.**

Doctors should not be involved in such things.

It should be known that I was an enthusiast for renal transplantation until heart transplantation came along and – because Terence English needed my help for his purposes – I had to look into the means of acquisition of viable hearts and, in consequence, declined to become involved. [Another cardiologist was appointed to enable him to get started in 1979]. It may also be worth mentioning that I was S.R on a Renal Unit, in the days before transplantation, when we could offer dialysis to only 3 of the 50-odd patients with chronic renal failure who came into our care each year. I might have been instrumental in a twin-to-twin transplant half a century ago had not the healthy brother proved to have a horseshoe kidney on IVP (as we called that procedure then). I suppose I was something of a pioneer by nature, remembering that I developed cardiac investigatory and resuscitation techniques in Birmingham, in the 1960s, and then brought modern cardiology to East Anglia – setting up coronary care units (and prevention clinics), teaching myself coronary arteriography (so that we could start coronary bypass surgery), establishing a regional pacemaking service (the most satisfying thing I ever did), and, recognizing its potential, introducing echocardiography at Papworth Hospital in the 1970s.
From these insights I hope it will be seen that I am not naturally opposed to progress. Nor am I unaware of the miseries of chronic dialysis – though it has to be said that I have also been most impressed by some who hold down highly active jobs while kept alive by such means (and by a retired high-ranking RAF officer who enjoyed flying with me before eventually “dying for want of a transplant”). I have also seen the transformation of life which a successful renal transplant can provide – to a close friend amongst others – and I have witnessed the disappointment failures bring, sometimes accompanied by accusations and criticism of those considered to have raised false hopes.

None of those things is relevant to my present – and almost certainly final – position which, as you know from your reading of what I have managed to get published, is based on true science and my understanding of a doctor’s duty towards his patient. The fundamental problem is that one cannot get transplantable organs – expected to function in the body of another for 10 years – from the truly dead. Hence the attempts to redefine death in an anticipatory sense for that purpose. All of them – the neurological and the recent faux circulatory – redefinitions are, as Shah et al. pointed out in J Med Ethics last year, no more than legal fictions – inventions for the purpose. Added to that are the terrible things certain members of our profession seem willing to do to their patients before they are in any sense dead when the condition of the wanted organs becomes the paramount consideration.

I have often wondered if I am wrong in my understanding of the neurological concepts and criteria of human death but, perhaps in consequence, I have become ever more convinced that the proper scientific attitude (to the critical consciousness element particularly) is “We just do not know”. That seems to be the assessment of the neuroscientific community outside Medicine wherever one can get it even to consider the matter. An authoritative view is that “Science cannot address the problem of consciousness” – though some Nobel Laureates have tried. Unless and until that changes, there can be no question of considering a brain dead while blood continues to circulate through it. How long, after the truly final cessation of all such blood flow, one must wait before deciding that a brain is dead is the question which requires scientific investigation for the provision of a reliable answer. It is, of course, a complex question requiring the consideration of variables such as prior nutrition, temperature, etc. My personal clinical observations suggest that (at ordinary temperatures) that period is greatly in excess of the waiting times currently in use for ‘DCD’ organ procurement. [I once resuscitated a neurologist after some 40 minutes of cardiac arrest – during which there was some ham-fisted chest compression/ventilation – and he returned to active consultant practice].

I have also wondered why I continue trying to make the truth about transplants known after some 35 years of pretty ineffectual effort. At first it was the bad science and intellectual dishonesty involved in calling brains “dead” when only tiny parts of them had been tested which motivated me. As time went by, the more powerful motive became concern about the deception of vulnerable people by those – particularly official bodies – intent on getting
more organs for transplantation, seemingly at any price. I sincerely doubt if all those millions whose names are on the NHS Organ Donor Register fully understand what they are deemed to have agreed to by ticking boxes offering their organs “after my death”. If they did not understand that they might be certified dead for that purpose on controversial criteria, not accepted in the USA, rather than the age-old criteria of death as commonly understood, they were deceived by the wording and their “consent” is invalid. If parents are not told, frankly and fairly in terms they can be expected to understand in their distraught state of mind, that their “brain stem dead” children will (although paralysed with drugs to facilitate the surgery) react during organ removal as if they might be suffering, then they have been most wickedly deceived (by omission). I could never have allowed one of my children to be used as an organ donor. To me, that would have been the betrayal of the absolute trust which a child has in his parents. I cannot imagine any parent who knew the facts, as I do, allowing his or her child to be so abused in departing this life. That some have been persuaded to agree to it forces me to conclude that they cannot have been fully and fairly informed.

As for the procurement of kidneys and parts of livers from healthy donors, I can only say that I don’t know how any doctor can operate on his patient not for his good but knowingly to do him harm.

Yours sincerely,

David Evans
Retired Consultant in Cardiology, Papworth & Addenbrooke’s Hospitals

A few key references:

1. Evans DW, Lum LC. 1980. Cardiac transplantation. Lancet 1, 933-4
4. Evans DW, Hill DJ. 1989. The brain stems of organ donors are not dead. Catholic Medical Quarterly 40, 113-121
Dear Delegates,

I very much appreciate your invitation to shed some light on Dignity in Donation. I am sorry that I have a previous commitment that I am unable to change. I must also say that, although my anxieties about the way in which we continue to obtain organs from those diagnosed as dead for transplant purposes and my desire for the truth, are undiminished, I become weary of the struggle after some 40 years.

I was involved in some early transplants as a senior registrar, and later as a consultant anaesthetist and witnessed some dreadful procedures. These included a liver "donor" child, supposedly dead, who out-lived the "recipient" child; an adult "donor" who commenced breathing (before operation) in theatre and was still alive and back in the Intensive Care Unit when relatives came to collect the death certificate the following day; and a dozen or so occasions when the Theatre Register gave the time of death of the "donor" as some hours after the commencement of the harvesting operation - presumably timing "death" as when respiration and circulation had finally ceased.. It will, no doubt, be said that the Register was inaccurately filled and that such events could not happen today, but one's memories remain. As do the problems.

The Diagnosis of Death for Transplant Purposes has no international consensus and in the UK (as Pallis asserted) depends upon testing only a few cubic centimetres of tissue in the brainstem for loss of function. Any activity in the higher brain is not looked for and can be ignored.

Live organs can only come from living bodies. Death is commonly associated with an apnoeic, cold, ashen grey, pulseless, stiffening corpse, and not the warm, pink, breathing (albeit with a ventilator), heartbeating, responsive "donor", and yet there is no requirement for explanation of the different conditions that will apply when a box is ticked for organs to be taken "after my death". Increasing pressure continues to be applied to obtain this far-from-fully-informed "consent" or, when that fails, to abandon any pretence by using increasing compulsion.

It is well documented¹ that those diagnosed as brain stem dead (BSD) respond to the trauma of surgery as for any other major operation by
hypertension, tachycardia and movement, and require paralysis and some form of anaesthesia for control. Neither the "donor" nor relatives need be appraised of this nor is anaesthesia offered or guaranteed on the donor card or register.

In the past I have been involved in [conferences] when, in spite of assurances to the contrary, donors and recipients are in the audience. As you, [Dr Gardiner], imply in your welcome cautionary remarks, it is simply not possible to confront those who themselves, or through their families (e.g. "a donor Mum's story") have been so involved, with the truths of these dubious procedures. Perhaps Deception in Donation would have been an alternative title.

The ethical dilemmas lie not so much, in the use of human organs for transplantation as in the means by which major organs are obtained. Corneas, for example, can be usefully transplanted many hours after death has been confirmed by traditional means and all life-support has been withdrawn. Kidneys can survive and recover function after a shorter period. Other major organs – such as the heart, lung, liver, pancreas et al. – must be taken whilst life-support continues and characteristics of life (heartbeat, circulation, respiration (albeit ventilator dependent), digestion, excretion, even maintenance of pregnancy, and response to stimulus continue.

Potential donors are unlikely to be familiar with neurological minutiae, but will easily recognise Fr Laurence’s description of Juliet’s appearance of death:

"no pulse
   Shall keep his native progress, but surcease:
   No warmth, no breath, shall testify thou livest;
   The roses in thy lips and cheeks shall fade
   To pearly ashes; thy eyes’ windows fall
   Like death when he shuts up the day of life;
   Each part depriv’d of supple government
   Shall, stiff and stark and pale, appear like death."

Romeo & Juliet Act 4, Scene 1

I am sorry if this is a disappointment to you and I sincerely hope that some, at least, of these things will be usefully aired.

With thanks and kind regards,

Yours sincerely,

Dr David J Hill
Retired Consultant Anaesthetist

References: -
