

**Is the United Kingdom Controlled Non-Heart
Beating Organ Donation Program Ethical?**

**CHB5206 BIOETHICS SUPERVISED
RESEARCH PAPER**

**for Master of Bioethics,
Monash University, Australia**

9th June 2006

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Introduction

Within nine months of Christiaan Barnard performing the world's first heart transplantation in Cape Town, South Africa, the Journal of the American Medical Association published two landmark papers, which provided the ethical framework necessary for the future of the emerging transplantation program. The first paper was the report of the Ad Hoc Committee of the Harvard Medical School who argued that irreversible coma, as met by their criteria, should be defined as a new criterion for death.¹ The accompanying, but lesser cited paper, was a Judicial Council ethical guidance by the American Medical Association to its members and the wider public regarding the emerging technology of solid organ transplantation.² Two ethical principles remained self evident to the Judicial Council and have been influential in transplantation debate ever since. Firstly the so-called 'Dead Donor Rule', "When a vital, single organ is to be transplanted, the death of the donor shall have been determined by at least one physician other than the recipient's physician"³; and secondly, "A prospective organ transplant offers no justification for relaxation of the usual standards of medical care"⁴, and "Full discussion of the proposed procedure with the donor and the recipient or their

¹ Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death (1968) "A Definition of Irreversible Coma" *JAMA* August 5, 205 (6): pages 337-40.

² Judicial Council of the American Medical Association (1968) "Ethical Guidelines for Organ Transplantation" *JAMA* August 5, 205 (6): pages 341-2.

³ *ibid* page 342, point 3. The publication of the Judicial Council ethical guidance alongside the report of the Ad Hoc Committee provided ethical support for the criteria of brain death even though no direct reference to brain death was made by the Judicial Council.

⁴ *ibid* page 342, point 2.

responsible relatives or representatives is mandatory.”⁵ I call this combined second principle the ‘Consenting Donor Rule’.

Despite nearly thirty years of successful organ transplantation both ethical principles remain controversial. The debate seems to arise from two distinct bodies of opinion. The first, a minority opinion in the literature but worldwide probably the most common objection to organ donation, is based on religious objection to the very basis of brain death being a declaration of death. The second opinion, perhaps disingenuously, is expressed by those who are generally strong supporters of the transplantation program but feel that the two principles are too strict and unnecessarily limit the numbers of organs potentially available to the ever increasing transplantation waiting lists.⁶

The emergence of controlled (Maastricht Category III) non-heart beating organ donation (NHBD) programs, has the potential to greatly increase the supply of organs by widening the source of donors, and should appear minimally controversial to both bodies of opinion.⁷ Generally, like the first heart transplantation there appears to be great enthusiasm and little criticism for the

⁵ *ibid* page 342, point 4.

⁶ For examples see: Zamperetti N, Bellomo R *et al.* (2004) “Irreversible apnoeic coma 35 years later: Towards a more rigorous definition of brain death.” *Intensive Care Medicine* 30: pages 1715-22 & Kerridge I.H. *et al* (2002) “Death, Dying and Donation: Organ Transplantation and the Diagnosis of Death” *Journal of Medical Ethics* 28(2): pages 89-94.

⁷ Controlled Category III NHBD is part of the Modified Maastricht Categories for NHBD. Further explanation will be found in the body of the dissertation and in Appendix A but essentially Category III donation represents the unconscious and dying intensive care patients, who have their life sustaining treatments withdrawn on grounds of futility and then after death has been declared using cardiovascular criteria, organ donation proceeds. Some of my arguments may well be applicable to the other categories of NHBD but this dissertation only addresses the ethics of Category III NHBD.

introduction of NHBD programs and the British Medical Journal described NHBD in a recent editorial as having the potential to increase the organ supply by 10-20% and representing “a challenge which the medical profession has to take up.”⁸ Any disquiet directed against NHBD has mostly concerned the timing criteria used for diagnosing cardiovascular death, and the potential for conflict of interest with the treating physician in deciding who is dying and thus suitable for NHBD.⁹

As a United Kingdom (UK) intensive care physician (intensivist) working in an Intensive Care Unit (ICU), which currently does not practice controlled NHBD but is under pressure to commence such a program, I believe there is a more fundamental objection to controlled NHBD as currently practiced and proposed for the UK. My objection stems from what I regard as the essential difference between donation after brain death and donation after cardiac death (NHBD). In controlled NHBD due to the haste required to recover the organs before ischaemia irreversibly damages the organs, the donation procedure must commence before death occurs. The donation procedure becomes part of the dying process in NHBD, whilst in donation after brain death it is not necessary for this to be so. The nature of this pre-morbid intervention in NHBD varies from country to country. In the United States of America (USA), a more explicit pre-morbid intervention policy is practiced, whereby it is

⁸ White S.A. & Prasad K.R. (2006) “Liver Transplantation from Non-heart Beating Donors: A Promising Way to Increase the Supply of Organs” *BMJ* 332: page 377.

⁹For a good review on these ethical issues see: Bell M.D.D. (2003) “Non-heart Beating Organ Donation: Old Procurement Strategy-New Ethical Problems” *Journal of Medical Ethics* 29(3): pages 176-81.

standard for physical procedures and medications to be given to the dying intensive care patient for the purpose of facilitating organ preservation and NHBD. More subtly in the UK the pre-morbid intervention takes the form of organisational and attitudinal changes to the dying process, in particular alterations to the timing of the withdrawal of life-sustaining treatments that will lead to death. I believe this pre-morbid intervention is treating the dying patient as a means to another's end. It will be my proposition that this violation of Kant's categorical imperative is more than just a failure in sentiment but a failure in the ethical treatment of the patient. The only way I believe it is possible to avoid this failure is if the donor has chosen NHBD as their own end. It is the failure to obtain *appropriate* consent for organ donation that I believe makes the current and proposed controlled NHBD program in the UK unethical.¹⁰

To support this proposition I wish to argue a number of points. Satisfaction of the Consenting Donor Rule is necessary for ethical organ donation. However, to begin the donation procedure before death has occurred violates the Dead Donor Rule. There are two legitimate reasons why such a violation might be ethical. The first reason is that the Dead Donor Rule is unnecessary or at least

¹⁰ Current practice is sourced from UK NHBD hospital policies I have accessed. I felt it was necessary to include proposed changes due to the impending changes in UK law regarding organ donation, namely the Human Tissue Act. For proposed practice I have sourced UK official society guidelines (The Intensive Care Society, British Transplant Society) and government publications (UK Transplant, Human Tissue Authority). These sources are available in my bibliography and when directly referred to they are referenced as footnotes throughout the body of the text. In all future references in the dissertation to the UK controlled NHBD program it should be taken as read that I am referring to current and proposed practice unless specifically stated.

less important than the Consenting Donor Rule. Adopting this belief would mean that the potential non-heart beating (NHB) donor, for the purposes of consent for organ donation, can properly be thought of as a Living Moral Agent, albeit with diminished capacity. The second legitimate reason is that the potential NHB donor, an unconscious and dying intensive care patient, can morally be regarded as dead already, thereby ethically satisfying the Dead Donor Rule. This can be based on the argument that death has become inevitable without any chance of regaining consciousness and, that they have already died as a person, even if not as an organism. Our treatment should thus resemble our treatment toward the dead, a Deceased Moral Agent. I do not intend to defend the Dead Donor Rule or choose which of the two options is ethically preferable. Instead I will consider each option in turn, Living Moral Agent and Deceased Moral Agent and argue that under the UK controlled NHBD program both breach the Consenting Donor Rule and on this ground are unethical.

If we consider the potential NHB donor as a Living Moral Agent then we must accept the need for consent that meets criteria for medical informed consent. That is consent, which is informed, voluntary, and the agent has the capacity to give. Naturally the unconscious and dying intensive care patient has no current capacity to consent for organ donation, or consent to anything else for that matter, but the consenting process should resemble that used in other situations where a person is incapable of giving their consent. The UK controlled NHBD

program consenting process does not ethically satisfy this standard and therefore breaches the Consenting Donor Rule. Alternatively the potential NHB donor can be considered as a Deceased Moral Agent, such that we should seek consent for organ donation in the same way as we currently do for the brain dead organ donor. Generally an attitude of Respect of Wishes is adopted toward the dead. Under the proposed consenting process for UK controlled NHBD but not I believe under the current consenting process, the Consenting Donor Rule will also be breached.

I will firstly address some necessary background into the history and practice of NHBD, with reference to current and proposed UK practice, and then I shall explore the two ethical transplantation rules, the Dead Donor Rule and the Consenting Donor Rule. This will lead me onto the moral options for treating potential NHB donors, Living Moral Agent or Deceased Moral Agent, and the implications for controlled NHBD. I intend to end on a positive note with suggestions as to what I believe would make a controlled NHBD program ethical.

II - Non-Heart Beating Organ Donation, Background and Practice

The first successful transplantation of any solid organ was in Boston 1954 when Dr Joseph E Murray transplanted a kidney from one live identical twin to another.¹¹ Most patients requiring organ donation do not have an identical twin and even if they do, other organs such as the heart and liver do not come in pairs. The goal at the time was to perfect organ retrieval from the deceased, necrodonation. Prior to the recognition of brain death, necrodonations were from patients who had been declared dead by traditional cardio-respiratory criteria. The early history of transplantation is thus a history of live donation and non-heart beating donation.

Let me make clear the difference between controlled NHBD and today's most common form of necrodonation, heart beating donation. The following table might help.

¹¹ Sayegh M. & Carpenter C.B. (2004) "Transplantation 50 years later – Progress, Challenges and Promises" *New England Journal of Medicine* 351(26): page 2761.

Types of Necrodonation UK / Australia Nomenclature	Non-heart beating donation (NHBD)	Heart beating donation (HBD)
Alternative USA Nomenclature	Donation after cardiac death	Donation after brain death
UK criteria used to diagnose death.	Traditional Cardio-Respiratory Criteria the irreversible cessation of cardiac and respiratory activity	Brain Stem Death Criteria ¹² representing irreversible cessation of brain stem function as manifested by irreversible loss of consciousness and the irreversible loss of the ability to breathe
State of the patient at the time of ventilation discontinuation.	Alive	Dead
The hearts activity at the time of the declaration of death.	Ceased	Beating
Usual time frame from the declaration of death to the time of surgical incision commencing the organ retrieval.	Less than 15 minutes	A few hours, often greater than four
Organ Warm Ischaemic Time	Practical UK minimum 15 minutes, often longer	< 1 minute
Common organs that can be used for transplantation	Kidneys Liver Lung	Kidneys Liver Lung Heart

¹² The controversy surrounding the theory and criteria for *whole* brain death verse brain *stem* death is something I will avoid exploring, as it serves no purpose to this dissertation. Since the UK, the subject country of this dissertation, practices brain stem death criteria any use of the shortened terminology brain death should be read as representing brain stem death.

The nomenclature is confusing and is not internationally governed. My personal preference would be to adopt the USA nomenclature of donation after cardiac death or after brain death because it clearly links the type of donation to the criteria used to diagnose death. This is a relatively new nomenclature so for the purposes of this dissertation I will stick to the less clear but more common terminology of non-heart beating donation (NHBD) and heart beating donation (HBD).¹³

Non-heart beat donation is different to HBD and not just in the criteria used to declare death. Firstly controlled NHB donors have their life-sustaining treatment withdrawn whilst they are still alive, whereas in HBD the discontinuation occurs following the declaration of death. Secondly, brain death is a very rare way to be declared dead and this rarity is limiting the donor organ pool. The major diagnoses leading to brain death and subsequent HBD are subarachnoid haemorrhage, head trauma and meningitis. Many more patients in the intensive care unit will die of these very same diagnoses but never satisfy the criteria for brain death. Instead when it is considered by an intensivist that death is inevitable and further treatment is futile, yet the patient does not fulfil brain stem death criteria, life-sustaining treatment including

¹³ NHBD versus HBD is a misnomer. In surgically retrieving the heart from the donor the heart is stopped just prior to the actual removal of the heart from the donor's body, such that it is technically non-heart beating at retrieval. The definitional difference must therefore be at the time of commencing surgical incision. Such confusing nomenclature is another reason why I would advocate the adoption of the USA terminology.

ventilation, will be withdrawn on the grounds of futility.¹⁴ The patient will die, death will be declared by traditional cardio-respiratory criteria and the organs will be buried with the rest of the body. Retrieving these organs immediately following the declaration of the donor's death by traditional cardio-respiratory criteria, a controlled NHBD program, could vastly increase the potential organ pool.¹⁵ It is the failure of HBD to meet the shortfall in donor organs that has prompted the renewed interest in NHBD. Thirdly, the major downside to NHBD and the reason it was originally abandoned in favour of HBD, is the increased warm ischaemic time compared to HBD, since cardio-respiratory failure must precede organ donation leading invariably to inadequate organ perfusion.¹⁶ In many controlled NHBD programs if the time of withdrawal to the time of organ retrieval exceeds two hours, then NHBD is abandoned. The increased warm ischaemic time compared to HBD makes heart transplantation technically impossible from NHBD at present, although experimental work continues, and the results of other organ transplants (kidneys and liver) worse.¹⁷ NHBD organs are generally regarded as sub-optimal but acceptable transplantation organs.

¹⁴ In UK intensive care units, fifty percent of all deaths follow a treatment withdrawal decision. Intensive Care Society (2004) "Guidelines for Adult Organ and Tissue Donation" Page 45.

¹⁵ The actual pathological diagnosis leading to death in NHBD is likely to be a similar neurological one to HBD. There is no requirement for this to be so, since the futility grounds used to justify the withdrawal of life-sustaining treatment need not have any neurological component. However systemic illnesses such as sepsis and trauma are likely to have resulted in multi-organ failure such that the organs will not be suitable for donation.

¹⁶ The time period from when blood perfusion is inadequate to meet the tissues needs to when the organ is perfused with cold fluids is known as the warm ischaemic time. The time period from cold perfusion to transplantation into the recipient is known as cold ischaemic time.

¹⁷ Delayed graft function for kidneys (27.5% NHBD vs 21.3% HBD) Cooper et al (2004) "Donation after Cardiac death: The University of Wisconsin Experience with Renal Transplantation" *American Journal of Transplantation* 4: page 1492. Primary failure in liver

The major approach to reduce these poorer outcomes from NHBD organs is to reduce the length and degree of warm ischaemic time. This has been attempted in a number of ways. By withdrawing life-sustaining treatment in the operating theatre instead of in the intensive care unit the time from the declaration of death to organ retrieval can be minimised. Or likewise by using cardio-respiratory death criteria that demand only a very short period of pulselessness before death can be declared.¹⁸ Alternatively, once death is certified by traditional cardio-respiratory criteria, external heart compression and oxygenation is commenced to maintain organ function and this organ resuscitation is continued right up to the time of organ retrieval.¹⁹ Another method to minimise warm ischaemia is to administer intravenous medication or perfuse the organs with fluids to enhance organ viability whilst the organs are still in the patient, via such devices as femoral lines. This can be commenced either before death, which is the preferred method to minimise warm ischaemia, or immediately after death. In the UK the primary method of reducing warm ischaemic time is organisational. The withdrawal of life-sustaining treatment in the ICU will not commence until all aspects of the donation process are in readiness.

transplantation (12% NHBD vs 6% HBD) White S.A. & Prasad K.R. (2006) "Liver transplantation from non-heart beating donors: A promising way to increase the supply of organs." *BMJ* 332: page 377.

¹⁸ The current recommendations to diagnose death by cardio-respiratory grounds are two minutes of pulselessness, as documented by an absent arterial line waveform, in the USA versus 5 minutes of asystole, as documented by the absence of electrical activity by an electrocardiogram in the UK. Presented at the Third International Conference on NHBD, London, May 11-12th 2006.

¹⁹ This is of considerable concern in potentially increasing the number of cases of Lazarus syndrome (auto-resuscitation) or theoretically might mean that brain function is re-established.

There are 13 NHBD programs in the UK.²⁰ Of the 750 necrodonations in the UK for the period 2004-2005, 86 (11.5%) were NHB donors, compared to 73 the previous year. Despite this there is, as of yet, no UK national NHBD program and each centre carrying out NHBD have needed to develop their own policy. More recently national bodies have published some guidance and in this dissertation I have drawn from the guidelines published by the UK Intensive Care Society, The British Transplant Society and more internationally the influential US Institute of Medicine 1997 & 2000 publications. I have sourced three individual hospital NHBD policies from the United Hospitals Birmingham, the Leeds Teaching Hospitals and the North Bristol NHS Trust; and I have attended the 3rd International Meeting on Transplantation from Non-heart Beating Donors, London, May 11-12th 2006. It is my intention not to directly criticise any one policy or guideline as I see the ethical failure in the UK controlled NHBD program as being of a more fundamental and endemic nature.

Let us consider an example of controlled NHBD as taken from an example used in the critical care literature for a published ethics debate concerning NHBD.²¹

²⁰ Statistics & Audit Directorate: UK Transplant (2005) "Transplantation Activity in the UK 2004-2005"

²¹ I have modified the example slightly so that nomenclature is consistent with UK/Australian usage and provided a few extra medical explanatory asides. All alterations are denoted by the use of [] square brackets. Taken from: Whetstone L, Bowman K & Hawryluck L. (2002) "Commentary Pro/con ethics debate: is nonheart-beating organ donation ethically acceptable?" Critical Care 6(3): page 193.

“Mr Robert Henry is a 45-year-old corporate executive who, while preparing to go to work, complains of a severe headache and collapses in front of his wife. As he is brought into the accident and emergency department, he is seizing [fitting]. He is quickly given intravenous midazolam [sedative] and phenytoin [anti-seizing medication], and he is intubated [a breathing tube is placed into his airway]. A computerized tomography [CT] scan reveals a devastating subarachnoid haemorrhage [brain bleed]. Neurosurgery is consulted, but in their opinion the patient will never regain consciousness and neither an angiogram [further radiological investigation and treatment] or an operation will be of benefit. Mr Henry has a living will stipulating that he is not to be kept alive on life support in the event of severe brain injury. After extensive discussions with the intensivist and the neurosurgeon, his wife and family agree to withdraw him from life support. At this time Mr Henry is not brain dead.

The hospital has a NHBD protocol that mandates that the intensivist should contact the [donor transplant co-ordinator (DTC)] whenever life support is withdrawn. Mr Henry meets their criteria for NHBD, and the [DTC] approaches his wife and family about donation. The wife consents to NHBD after further discussions with the [DTC] and the intensivist, even though Mr Henry had never discussed his thoughts on the issue, since donation would mean some ‘good’ could come from this devastating event.

Premortem central venous cannulation [medical catheter placed into a major vein of the body] is required in NHBD to infuse organ preserving solution and heparin (unless contraindicated [since heparin thins the blood and could lead to further bleeding potentially leading to criticism that it was the heparin that hastened his death]). Separate consents for NHBD, cannulation and heparinisation must be obtained from the family. Heparin is contraindicated in this case since it would worsen the subarachnoid haemorrhage.

The central line is inserted. Mr Henry is taken to the operating theatre with his family in attendance. He is extubated [breathing tube removed], and narcotics [analgesics] and benzodiazepines [sedatives] are given to palliate his dyspnea [rapid and laboured breathing] and his discomfort. Death is pronounced and, after a period of 5 min of asystole [lack of cardiac electrical activity as assessed by electrocardiogram tracing], of an absence of a pulse and blood pressure via the arterial catheter or noninvasive blood pressure monitor and of an absence of respirations, the preserving solution is infused via the central line. His wife and family leave the operating theatre and his organs are harvested [retrieved].

This North American example is usefully contrasted to UK controlled NHBD practice and a number of points of difference can be made. The use of living wills (advanced directives) is increasing in the UK but is an uncommon situation in intensive care. The initial contact with the family concerning organ donation would most likely come from the intensivist but more and more often this is being done with the prior involvement of the DTC (donor transplant coordinator). Surrogate consent is not legal in England and Wales but it is in Scotland. England recognises medical Best Interests as decided by the treating physician. Potential donors are checked for on the UK NHS Organ Donor Register before the family is approached. If they are on the registry, the use of this information when discussing donation with the family, is believed to significantly improve the chances for the family consenting for donation. Pre-mortem cannulation and moving the patient to the operating theatre for treatment withdrawal is against the UK Intensive Care Society (ICS) guidance.

III – The Two Rules for Ethical Organ Donation

The pro/con ethical debate that accompanied the above example focussed primarily on one particular ethical aspect, the timing and criteria used to declare death, and therefore whether or not the Dead Donor Rule had been satisfied.²² Whilst robust criteria for death is medically and socially important I contend that the Dead Donor Rule was breached the moment the donation procedure commenced; that is the moment the donation procedure became part of Mr Henry's dying process. Specifically the pre-mortem cannulation and the organisational and attitudinal changes that occurred once Mr Henry moved from being considered as an unconscious and dying intensive care patient to an organ donor. Importantly this breach of the Dead Donor Rule is an essential part of any successful NHBD, whereas in HBD there is no necessity for it to be so, as all donation preparation can await the declaration of death.

I believe there are three responses that can be made to this contention that NHBD breaches the Dead Donor Rule. The first is to deny the breach by claiming that the interventions on Mr Henry were trivial and that I have overstated their nature; the second is to claim that the Dead Donor Rule is unnecessary, or at least less important for ethical organ donation compared to the Consenting Donor Rule; and the third is that Mr Henry, as an unconscious and dying intensive care patient is morally dead already, therefore the Dead

²² The dead donor rule came out of the Judicial Council statement, "When a vital, single organ is to be transplanted, the death of the donor shall have been determined by at least one physician other than the recipient's physician." Judicial Council of the American Medical Association (1968) "Ethical Guidelines for Organ Transplantation" *JAMA* August 5, 205 (6): page 342.

Donor Rule was satisfied. I propose that the first response is mistaken. When the claim of triviality is considered its justification is dependent on one or both of the other responses without acknowledgment of this truth. I hold the second and third responses as valid and in need of exploration.

Were the pre-mortem interventions on Mr Henry trivial and have I overstated their nature? The UK ICS state in their guidelines for NHBD that once a decision to withdraw has been reached:

“It is inappropriate to escalate current treatment, add new therapies (e.g. inotropes, heparin, hormone replacement) or to undertake invasive interventions (e.g. vascular cannulation before death for cold perfusion) to improve organ viability... Withdrawal of active treatment should usually take place within the critical care unit. In exceptional circumstances treatment may be withdrawn within the theatre complex (e.g. an anaesthetic room, recovery area). This should be undertaken only as a way of meeting the patient’s and relatives’ wish to donate organs and not simply as a means of reducing warm ischaemic time.”²³

The UK ICS rejects the USA practice for pre-morbid physical intervention.

The UK justification is not stated in the guideline but it is likely to be that pre-morbid physical interventions, trivial or not, cannot be sanctioned because they offer no medical benefit to Mr Henry instead, by reducing warm ischaemic time, they are for the benefit of the future recipient of Mr Henry’s organs. The USA counter argument I believe would be based on the grounds that Mr Henry’s legal surrogate, Mrs Henry, has consented to these interventions. As one US speaker at the 3rd International Meeting on Transplantation from Non-heart Beating Donors said in challenge to the pre-

²³ Intensive Care Society (2004) “Guidelines for Adult Organ and Tissue Donation” page 46-47.

dominantly UK audience and the known UK objection to pre-mortem intervention, “If you [the organ donor] do want to donate organs you don’t want to donate bad organs.”²⁴ This USA attitude I would argue is to advocate that it is not the Dead Donor Rule, which is important but the Consenting Donor Rule. In England and Wales surrogate consent is not recognised but even in other countries where it is, it would be unusual for surrogate consent to allow for medical treatments that have no medical benefit for the patient.²⁵ Even in the UK under current and proposed controlled NHBD programs Mr Henry’s death would have been altered according to two main factors, the timing of the withdrawal of life-sustaining treatments and the attitude to the dying whereby the organs gain priority over the person. This allegedly trivial alteration in the dying process can be seen in one UK NHBD policy I reviewed where, when discussing resource implications for a NHBD program, the conclusion was it would be minimal since in NHBD life-sustaining treatment would generally be withdrawn in working hours whilst in HBD resources would need to facilitate 24 hour donation.²⁶ HBD occurs on deceased individuals. The timing of organ retrieval is chosen to maximise organ viability and not for the benefit of the donor. For the unconscious and dying intensive care patient where it is believed that further treatment is futile and life-sustaining treatment should be withdrawn, to delay this withdrawal to a

²⁴ Dr DeVita in his lecture “Changing Practice in NHBD” 3rd International Meeting on Transplantation from Non-heart Beating Donors, London, May 12th 2006.

²⁵ It might be argued that it is in Mr Henry’s overall benefit to organ donate, he had a strong wish to donate for example. This I would contend is still to say that it is the Consenting Donor Rule which is important not the Dead Donor Rule. This is explored in greater detail in Section IV: Living Moral Agent.

²⁶ I have not specifically given this reference, as I do not wish to attack any one individual policy. All of the policies I reviewed are referenced in my Bibliography.

time convenient to the transplantation team is to treat the NHBD like the heart beating donor, as dead already.

To further demonstrate that altering the dying process should not be regarded as trivial, consider the following slippery slope examples. Warm ischaemic time is the main technical limitation for NHBD. If the pre-mortem interventions on the potential NHB donor are trivial (cannulation, medications etc), and especially trivial because Mr Henry is unaware of them, why could we not avoid warm ischaemia altogether by taking Mr Henry's kidney and liver before the withdrawal of life-sustaining treatment? This is to directly say that the Dead Donor Rule is itself trivial. Alternatively if the triviality is the short delay required in NHBD for withdrawal while the retrieval team and all other aspects of transplantation are prepared, consider: what if the retrieval team was unwilling to travel to a particular hospital but asked for the unconscious and dying potential NHB donor to be transferred to their ICU for withdrawal of life-sustaining treatment and eventual donation. This situation could theoretically be imagined for Mr Henry if his original intensive care was considered particularly obstructionist and ambivalent toward organ donation. How is such a transfer to Mr Henry's medical benefit? Although unconscious it is not inconceivable for the transfer to involve him some physical pain or require a deepening of his analgesia and sedation. His vital physiological parameters might start to fall during the journey would it not be trivial to

increase the medications to support him just that bit more? We would be treating Mr Henry as dead already and his organs more important than he is.

I contend that the Dead Donor Rule was breached the moment the donation procedure became part of Mr Henry's dying process. I do not believe one can legitimately deny this contention by claiming that the breach was trivial and overstated. Such an attitude is incoherent because it fails to acknowledge the underlying justifications implicit in the claim. The claim is dependent on either refuting the Dead Donor Rule or treating the patient as dead already. It is my personal impression however that the claim of triviality is the most commonly held view from those working in donation and the general public. This is a reflection of the very attitudinal change toward the potential NHB donor that I am critical of.

I outlined above that solid valid arguments could be made to justify this breach in the Dead Donor Rule. These arguments do not contend that the breach is trivial and overstated but instead argue strongly for the breach being justifiable. The two legitimate individual responses to the breach are that the Dead Donor Rule is unnecessary for organ donation, or is at least less important than the Consenting Donor Rule; or that Mr Henry, as an unconscious and dying intensive care patient is morally dead already therefore the Dead Donor Rule was satisfied. It is not my intention in this dissertation to choose between the two responses but instead consider the implications for the

NHB donor if we accepted either of the responses. Firstly I will elaborate why one could hold either of the two responses as valid.

Norman Fost in his article, “Reconsidering the Dead Donor Rule: Is it Important that Organ Donors be Dead” argues that the Dead Donor Rule is conceptually and medically flawed.²⁷ He makes four points why this might be so.²⁸ Firstly since death is a process, conceptually there might be no moment of death and therefore the Dead Donor Rule can never be satisfied. Secondly that ‘whole brain death’ as practiced in the USA is medically flawed as some brain function still continues and yet many thousands of patients have had organs removed who are not dead by whole brain death criteria. Thirdly that the growing expansion of live organ donation to ‘strangers’ suggests we could hold that, “A patient, while still competent may choose to have organs removed prior to death, through an advanced directive”.²⁹ Finally, that the Dead Donor Rule stands in the way of improving organ supply by prohibiting organ removal from patients who have ‘little to lose’, such as those in persistent vegetative states and presumably, but not discussed in his article, those who are unconscious and dying in intensive care, the potential controlled NHB donor. One of the pillars of the Dead Donor Rule acknowledged by Fost is, “...that it is wrong to invade a person’s body without the informed consent of the patient or an appropriate representative, or, if consent is not possible,

²⁷ Norman Fost (2004) “Reconsidering the Dead Donor Rule: Is it Important that Organ Donors be Dead” *Kennedy Institute of Ethics Journal* 14(3): page 251.

²⁸ *ibid* pages 249-260.

²⁹ *ibid* page 252.

unless it is clearly in the patient's interest."³⁰ According to Fost therefore it is the Consenting Donor Rule which is paramount not the Dead Donor Rule. If so we must seek *appropriate* consent from the unconscious and dying intensive care patient, the potential controlled NHB donor, before the donation procedure commences. The donor should continue to be regarded as a Living Moral Agent, the same as for any other unconscious intensive care patient. This will be explored in Section IV entitled 'Living Moral Agent'.

The alternative response is to claim that the unconscious and dying intensive care patient is morally dead already and therefore that the Dead Donor Rule is satisfied. Why could we hold such a view? Peter Singer in his book 'Rethinking Life and Death' uses as an example an epitaph written on the funeral stone of a woman, Nancy Cruzan who died many years after being in a persistent vegetative state. The epitaph on her tombstone read, "Departed Jan 11, 1983; At Peace Dec 26, 1990"³¹. The unconscious and dying intensive care patient is not going to regain consciousness. It is unlikely that they are or will experience anything. If personhood is any of the following characteristics: seeing oneself existing over time, rationality, experiencing of sensations, or goal setting; then it can be said that the person known as Mr Henry has died prior to donation.³² The question then becomes what moral obligations do we

³⁰ *ibid* page 252.

³¹ Singer P. (1994) "Tony Bland and the Sanctity of Human Life" *Rethinking Life and Death*. Text Publishing: Melbourne: page 62.

³² John Fischer claims in the introduction to his edited book 'The Metaphysics of Death' (1993) Stanford University Press California, "These properties – consciousness, rationality, and free will – can help us to demarcate the boundary between persons and nonpersons." page 13.

have to the dead when it comes to controlled NHBD? This too is a matter concerning *appropriate* consent and I will offer an exploration in Section V entitled, 'Deceased Moral Agent'.

Internationally the appropriate consent for necrodonation varies. The Anglo-Saxon countries according to Nora Machado, such as England, Australia and North America, with our strong normative concepts of individual rights and property rights have voluntary consent systems, which see donation as an altruistic gift.³³ Other countries have presumed consent systems but even in these countries typically the family of the deceased is consulted.³⁴ All Western countries no matter which system of consent they apply allow for prior patient refusal to donation. The Consenting Donor Rule, although variably applied, still holds. Is this justifiable? At first glance my instincts say an absolute yes, yet because the ethics of donor consent is pivotal to this dissertation I feel I cannot pass over this question without some further exploration.

The very word 'donor' has connotations of giving that suggests the need for consent, as without consent there is no giving only taking. The rise of the importance of consent in medical practice and in the abandonment of traditional medical paternalism is tied to the rise in patient autonomy. This individualistic philosophy has its origins in Kantian respect for the person and

³³ Machado N. (1998) "Organ Procurement" *Using the Bodies of the Dead: Legal, ethical and organisational dimensions of organ transplantation*. Ashgate Dartmouth: Aldershot: Page 44.

³⁴ Denmark is the only European country with a system of strong presumed consent where the family of the deceased is not consulted before organs are taken. IBID page 44.

the utilitarian John Stuart Mill who said that, “Over himself, over his own body and mind, the individual is sovereign”³⁵ Autonomy is valuable because it tells us that every person is of worth and has dignity, promotes beneficence by suggesting we have a duty to actively aid the ends of others, and it allows us to follow our own values. But could we envisage a transplantation program where consent is not required? It could be considered that organs do not belong to the person who utilised them in life but that they belong, especially after death, to society. I find it hard to justify this attitude unless the society we lived in also claimed that all of our estate is owned by the society after death, since it appears to me difficult to say that there is a difference between my organs that might help another member of the society and my money. Alternatively, and more dramatically, in a world where consent was not required for organ donation and having also abandoned the Dead Donor Rule, a frightening door opens on the ultimate utilitarian claim that I am sitting here writing and utilising organs that is keeping only one life alive but if I was killed for my organs then my organs could be keeping five or more people alive.³⁶ I believe that the Consenting Donor Rule stands, if not incontestable, at least as a moral check on any form of organ donation.

³⁵ Mill, J.S. (1979) "Introduction / Applications" in Warnock, M.(Ed.) *Utilitarianism, on Liberty, Essays on Bentham* Collins:London: page 135.

³⁶ This argument is reminiscent of John Harris’ survival lottery whereby a random ‘donor’ would be chosen for organ retrieval but that overall, the donor had a statistically higher chance in benefiting from another person’s organs than to have their organs retrieved. Harris J. (1975) “The Survival Lottery” *Philosophy* 50(191): pages 81-7.

What remains to be considered in this dissertation is how the Consenting Donor Rule should be applied to the unconscious and dying intensive care patient, the potential controlled NHB donor. If we consider the Dead Donor Rule as unnecessary then we need to establish how the Consenting Donor Rule should be applied to these Living Moral Agents. If instead we consider the potential controlled NHB donors as morally dead already, then we need to establish how the Consenting Donor Rule should be applied to Deceased Moral Agents, a situation akin to the current situation with HBD.

IV – Living Moral Agent

In this section we are to accept that beginning the donation procedure prior to death in a Living Moral Agent is ethically acceptable if having rejected the Dead Donor Rule, we still satisfy the Consenting Donor Rule. Accepting this premise certainly allows for an active euthanasia policy provided consent is obtained. Again it is not my intention to either accept or refute the Dead Donor Rule, or advocate euthanasia, but instead I seek to demonstrate how the Consenting Donor Rule is breached by the UK controlled NHBD program.

Michael Gill is a modern advocate for a model of presumed consent where the default position is that individuals do prefer to donate their organs for transplantation after their death unless they have actively registered their objection.³⁷ He makes an interesting division in his attitude to autonomy and consent. Gill contends that in life, the model of autonomy most important for others to adhere to is one of non-interference, which requires specific informed consent by the person to countenance any interference; whilst after death, since the person is no longer capable of determining the fate of their body and others must do it for them, respect of wishes is the model of autonomy others should adhere to.³⁸ I will refer to Gill's two models of autonomy as the 'Non-interference' model and as the 'Respect of Wishes' model. Gill's main claim is that we wrongly suppose a Non-interference model of autonomy on the dead, where this is simply not possible that they be left non-interfered with, but

³⁷ Gill M (2004) "Presumed Consent, Autonomy, and Organ Donation" *Journal of Medical Philosophy* 29(1): pages 37-59.

³⁸ *ibid* page 44.

instead Respect of Wishes is the model of autonomy that should be applied. His argument contends that since 70% of Americans in a Gallop Poll in 1995 indicated that they would be prepared to be an organ donor after death overall there would be fewer mistakes in wish adherence in a system of presumed consent. A system of presumed consent defends a notion of autonomy by making it more likely that most people have their wishes adhered to. Thus he uses arguments from consent and autonomy to advance a model of presumed consent. I will not seek to argue a case either for or against presumed consent but I accept that Gill's models of autonomy are correct.

Let us return to the original example of Mr Henry who suffered a severe brain haemorrhage. Now from Gill the correct moral treatment, since Mr Henry is alive, is one of non-interference, which requires specific informed consent by the person to countenance any interference. If Mr Henry were awake and conscious then gaining his informed consent would present little trouble. Unfortunately Mr Henry is unconscious and cannot give his informed consent. In fact, if the neurosurgeon is right, and for the sake of this example he is, Mr Henry will never regain consciousness. This situation of irreversible unconsciousness is very akin to Gill's judgements about death, since Mr Henry is no longer capable of determining the fate of his body and others must do it for him. Gill might therefore hold that we should instead adopt his other model of autonomy he used for the dead, a model of Respect of Wishes. Respecting wishes is certainly an appropriate aim but if we are to treat Mr Henry as a

Living Moral Agent then it is premature to abandon the model of non-interference even in the face of unconsciousness. As Beauchamp and Childress state, "...decisions about treatment properly belong to the incompetent or nonautonomous patient by virtue of rights of autonomy and privacy."³⁹

Unconscious and incompetent patients are a common situation in intensive care; in fact they are the norm. We should therefore adopt the same attitude toward the potential NHB donor as we do to any other intensive care patient.

How then can we gain consent in the unconscious and dying? I propose that for Gill's non-interference model of autonomy we should adopt a hierarchy of consent to allow for medical interference.⁴⁰

Hierarchy of Consent to allow Medical Interference

1. Current Expressed Informed Consent
2. Prior Expressed Informed Consent
3. Best Interests with Next-of-Kin (NOK) Assent
4. Best Interests or NOK's Wish

This hierarchy is supported by my reading of Beauchamp and Childress who suggest a hierarchy for incompetent persons with explicit prior autonomous

³⁹ Beauchamp T. & Childress J. (2001) "Respect for Autonomy" *Principles of Biomedical Ethics 5th Edition*. Oxford University Press: Oxford: page 99.

⁴⁰ It is not possible in this dissertation to formerly defend the hierarchy. Each point on the hierarchy should have its own set of criteria that must be satisfied for it to be considered valid. Best Interest I take to accord with the UK General Medical Council Guidance, see Appendix B.

judgments at the top and best interests below.⁴¹ It is also supported by Fost who I quoted above.”⁴² This hierarchy, in my experience, represents the practical approach taken by intensivists when dealing with patients in the UK and Australia.

Let us consider Mr Henry and NHBD using this proposed hierarchy. He is unconscious and dying. He cannot give Current Expressed Informed Consent but unusually he has given us prior consent in the form of his *valid* Living Will stipulating that he is not to be kept alive on life support in the event of severe brain injury. From this the doctors rightly conclude that the withdrawal of life-sustaining treatment is appropriate and end of life care should begin. Mr Henry however is suitable for NHBD. NHBD cannot occur, as I have argued, without some pre-mortem interference with his dying process. For Mr Henry this involved pre-mortem cannulation, were he to be a NHB donor in the UK where pre-mortem cannulation is considered inappropriate other aspects of his dying process, such as the timing of the withdrawal of life-sustaining treatment, would be altered for the purpose of facilitating NHBD. From our hierarchy Mr Henry cannot express his consent and he has left no prior expression of his consent for organ donation. In this North American example the doctors then sought surrogate consent from Mr Henry’s wife.

⁴¹ *ibid* pages 98-103.

⁴² “...that it is wrong to invade a person’s body without the informed consent of the patient or an appropriate representative, or, if consent is not possible, unless it is clearly in the patient’s interest.” Fost N (2004) “Reconsidering the Dead Donor Rule: Is it Important that Organ Donors be Dead?” *Kennedy Institute of Ethics Journal* 14(3): page 252.

Can Mr Henry's wife consent on his behalf to this alteration to his dying process? I propose in my hierarchy that she can't, that the next step is Best Interests with Next-of-Kin (NOK) Assent.⁴³ This contrasts to the Consenting Donor Rule as stated by the Judicial Council in 1968 which specifically allowed for consent in deceased donors to come from, "responsible relatives or representatives".⁴⁴ I suggest that neither Mrs Henry nor any NOK can fulfil this role for another Living Moral Agent. This opens onto a debate regarding the role of surrogate consent in incompetent patients that is beyond the scope of this dissertation but I will make two points. Firstly, if we consider the example of an unconscious Mr Henry having a small brain bleed that is potentially fully recoverable but Mrs Henry refuses to give consent to life-saving treatment. The role of the NOK is to ensure that the decision regarding Best Interests is fully informed. NOK assenters must still respect the Best Interests principle and altering Mr Henry's death is not in his best interests. Secondly, in the United Kingdom, the subject country for this dissertation, Mrs Henry has no legal right to make treatment decisions on behalf of Mr Henry. She can only assent to his treatment withdrawal not consent. In which case, neither would she be entitled to consent to the donation procedure commencing prior to Mr Henry's death. Yet this is what the UK controlled NHBD program is asking her to do.

⁴³ I would hold that in countries that allow Advanced Directives to state an actual person (surrogate) for the purposes of making medical decisions in the event of incompetence, such as the law in Scotland, then this would be part of Prior Expressed Informed Consent. To make such an Advanced Directive is a much greater expression of informed autonomous will than merely having a wife or next-of-kin, who acts as surrogate automatically.

⁴⁴ Judicial Council of the American Medical Association (1968) "Ethical Guidelines for Organ Transplantation" *JAMA* August 5, 205 (6): page 342, point 4.

Doctors as well as satisfying Best Interests have an additional duty toward Mr Henry. They must provide standard treatment, as suggested by the original 1968 Judicial Council ethical principles for transplantation and part of the Consenting Donor Rule.⁴⁵ The doctor as a professional healer authorised by the society Mr Henry lives in has a duty to heal if healing is possible and at the very least provide standard treatment. Mr Henry cannot expect this duty to be rescinded without his express wish and if unconscious he must understand and accept, however disappointing to him and his desires, that there is a strong probability the doctor will not deviate from this standard treatment. It is for this reason that Jehovah Witnesses know they must go to great lengths to ensure their local doctor, their medical records and their wallet indicates their strong held desire not to receive blood.

Without some strong statement from Mr Henry prior to death expressing a desire to organ donation and I would argue, specifically allowing the donation procedure to commence prior to death, Best Interests cannot be used to justify NHBD. All of the UK policies I reviewed allow for controlled NHBD to commence on the basis of family lack of objection, the exact same consenting process as used in HBD.⁴⁶ This I would claim is additionally to treat the potential NHB donor as dead already. It is wrong to alter the dying process for

⁴⁵ Judicial Council of the American Medical Association (1968) "Ethical Guidelines for Organ Transplantation" *JAMA* August 5, 205 (6): 341-2.

⁴⁶ The move in the UK to seek 'Family Lack of Objection' rather than consent demonstrates, I believe, how unimportant and muddled the issue of consent is becoming in UK donation even for HBD.

the benefit of others without the consent of the donor or without it being in the donor's Best Interests.

The final point in the hierarchy is Best Interests or NOK's Wishes. This could exist where there is conflict between the medical team and the NOK. In such a situation both parties would claim that the other party is misinformed about best interests. Often a third party, such as the judiciary, will be necessary to decide best interests. Rare examples could be imagined where there is no surrogate or even rarer, where the Best Interests calculation is neutral and the NOK must decide treatment.

NHBD cannot be seen as in the patient's Best Interests using the Hierarchy but proponents for NHBD would make two claims concerning consent and autonomy to justify a NHBD program. The first is that Best Interests equates to respect of wishes. The donor wishes to donate and therefore the best interest is the one that closest matches their wish. The second is that registration on an organ Donor Register would satisfy the hierarchy Prior Expressed Informed Consent.⁴⁷ I would argue that a model of autonomy Respect of Wishes is correctly assigned by Gill to the treatment of the dead. The dead cannot insist on a model of non-interference but only on Gill's model of Respect of Wishes,

⁴⁷ It might be argued that having registered on the Donor Register and having a strong wish for organ donation as volunteered by the family to the medical team, that this should be regarded as constituting Prior Expressed Informed Consent. I have some sympathy for this view and it was for cases like these that Leeds commenced its NHBD program. However these are exceptional cases and under the present consenting system the medical team would be altering the dying process on less assurance.

since as Gill states literal non-interference is not possible.⁴⁸ Nor can we choose to treat a Living Moral Agent in a way that would oppose a Best Interests principle or abrogate the duty of doctors to provide standard treatment without some strong expression of dissent by the person either currently or in the past. This is because without this strong expression of dissent we have inadequate information to do otherwise.

The UK NHS Organ Donor Register, as administered by UK Transplant, might be regarded by some as satisfying the hierarchies Prior Expressed Informed Consent category. I believe however the Donor Register falls well short of this. To qualify as informed consent, consent must be voluntary, made by a competent person and informed. Registration on the UK NHS Organ Donor Register fails to inform. This is especially true when it comes to NHBD. I believe most people would assume that the donation procedure occurs after you are dead, but as I have demonstrated, in NHBD it begins pre-mortem. I accessed the on-line UK NHS Organ Donor Register to explore the site with regard to its ability to satisfy criteria for informed consent.⁴⁹ The UK NHS Organ Donor Register fails to inform regarding NHBD. When as a clinician I consent my patients for any procedure part of the informing process generally

⁴⁸ Gill M. (2004) "Presumed Consent, Autonomy, and Organ Donation" *J Med Phil* 29(1): pages 45.

⁴⁹ UK NHS Organ Donor Register accessed 17/05/2006.
http://www.uktransplant.org.uk/ukt/how_to_become_a_donor/questions/questions.jsp
Certainly the register is voluntary but it is potentially concerning that anyone could register for anyone else. It was impossible to judge the capacity of those who register but I have no reason to suspect a problem. Regarding informed, in only 2 parts of the 46 questions "Organ Donation – Your questions answered" is NHBD mentioned, and only once by name. In neither mention were any negative points raised. Running alongside the questions and answers is an ever-changing section entitled "Why I want to be a donor?"

includes explaining to the patient a long string of negatives that might occur with the procedure. While listing negatives is not a perfect method for informing it is a useful one. The UK NHS Organ Register has no negatives expressed for *any* aspect of organ donation. Its purpose does not seem to be one of informing but persuading. Nor have the many members already registered been notified (informed) about the introduction of NHBD programs in the UK.⁵⁰ As well at no point in the on-line registration process is there an option to opt out of NHBD.⁵¹ The West Australian Government 2000 report into organ donation appropriately questions whether registration on a donor register is informed consent and describes donor registration as intent not consent.⁵²

In summary, if we are to treat an unconscious and dying intensive care patient, a potential NHB donor, as a Living Moral Agent, we must have as our standard a model of autonomy that will only allow medical interference if we have informed consent, either current or prior from the patient. The UK consenting process for NHBD is not informed and cannot be considered consent. Failing our ability to gain informed consent we must act in a patient's Best Interests. Since NHBD requires that the donation procedure becomes part of the dying process, without Prior Expressed Informed Consent that the

⁵⁰ Personal communication by a UK Donor Transplant Co-ordinator who wished to remain anonymous.

⁵¹ Completed the on-line registration process for the UK NHS Organ Donor Register on the 17/05/2006. In fact there is no on-line mechanism for registering a desire not to be on the organ register.

⁵² Standing Committee on "Uniform Legislation and Intergovernmental Agreements (2000) Organ Donation and Transplantation" *Western Australia Legislative Assembly* Report Number 25: page 8.

patient strongly desires to donate when dying, it cannot be known if it is in the patient's overall Best Interests to donate, and therefore the doctor and NOK must maintain standard treatment. Therefore I would hold that the UK controlled NHBD program is unethical.

V – Deceased Moral Agent

It might be considered that the above section gives the unconscious and dying intensive care patient too much moral agency. Mr Henry has suffered a severe brain haemorrhage. The neurosurgeon believes that he will never regain consciousness. Perhaps our attitude toward Mr Henry should be closer to our attitude to the dead rather than the living, since it can be argued that Mr Henry, as a person has died even if not as an organism. If so, treating him as dead will satisfy the Dead Donor Rule. In this section, I am intending to develop a different notion of autonomy, based on Gill's 'Respect of Wishes', that as Gill suggests is a more appropriate model for using when dealing with the dead. I want to explore the consequences for NHBD if we were to regard the potential NHB donor as a Deceased Moral Agent.⁵³ We must first answer the question: what moral obligations do we owe to the dead?

My colleague recently risked broken limbs and charges of trespass to clamber over derelict fences to reach a duck pond, where in accordance to his dead mother's wishes, he scattered her ashes. He went to great lengths to respect his mother's wishes. Why would he go to such lengths, when it could be considered that his mother could never know or even be pleased by his action? Why too should he feel any moral obligation to divide his mother's estate according to her 'Last Will and Testament'? And finally why should it even

⁵³ This section may have equal application to organ donation from the brain dead.

matter if Mr Henry is on the donor register since the only consent we require is from the owner of Mr Henry's corpse?

Gill takes the:

“Treating a person's body after her death in a way she did not want it to be treated is a wrong done to her in the same way disposing of a person's estate in a way she did not want it to be disposed of is a wrong done to her. We have a powerful moral duty to respect a person's wishes about what should happen after her death to the things that belonged to her.”⁵⁴

The right treatment of the dead, according to Gill, is the one that most frequently matches the wishes of the dead. Therefore it is right according to Gill that my colleague scattered his mother's ashes over the duck pond, that her estate was divided in accordance to her will and that Mr Henry donated his organs, if that was his wish.

A number of important questions arise. Are Gill and our own intuitive feelings correct, that to not respect a dead person's wishes is a harm? This I believe needs further exploration since if we decide otherwise, then there would be no need to have organ donor registers and seek to respect donor wishes, as the organs from the dead would belong to the owner of the corpse, either a relative or the state. With regard to wishes, how are we to know the wishes of the dead and is maximizing the frequency of fulfilled wishes of the dead the only morally important action?

⁵⁴ Gill M (2004) “Presumed Consent, Autonomy, and Organ Donation” *J Med Phil* 29(1): page 44.

Can the dead be harmed by failing to respect their wishes? The Epicurean argument is that since Mr Henry no longer experiences then whatever treatment we decide for Mr Henry, it will be of no concern to him.⁵⁵ Whatever hopes, aspirations or wishes Mr Henry had are now no longer and since Mr Henry cannot be harmed by our actions, we can treat Mr Henry, including the taking of his organs, as we the living wish.

Joel Feinberg argues that the dead have interests that survive their death, such that if these interests are harmed posthumously, then it can be said that the dead person has been harmed.⁵⁶ Feinberg believes that, “The final tally book on a person’s life is not closed until some time after his death.”⁵⁷ The interests that might be thwarted after death according to Feinberg are such things as, the abrogation of wills, the breaking of promises or the spreading of false rumours. Feinberg is forced to defend a number of potential criticisms. What interests can the dead have, how can a person be harmed though they do not experience the harm and who is the subject of the harm and when does the harm occur, since the person who has been harmed no longer exists? Feinberg develops his defence along a number of lines. Firstly that interests are derived from and linked to wants. Applying W.D. Ross’s distinction between want-fulfilment and want-satisfaction, want-satisfactions must be experienced but want-fulfilments need not be, since “the *fulfilment* of a want is simply the

⁵⁵ Fischer J.M. (1993) “Introduction: Death, Metaphysics, and Morality” in John Martin Fisher’s (Ed) *The Metaphysics of Death*. Stanford University Press: Stanford: pages 16-19.

⁵⁶ Feinberg J. (1993) “Harm to Others (Originally published in 1984)” in John Martin Fischer (Ed) *The Metaphysics of Death*. Stanford University Press: Stanford, pages 171-190.

⁵⁷ *ibid* page 176.

coming into existence of that which is desired.”⁵⁸ Since a person, is by their nature, future thinking and see themselves existing over time, so too will we see our interests existing over time. The interests that persist after death are those, which can be helped or harmed by posthumous events.⁵⁹ Feinberg defends the notion that the dead can be harmed, even though they can not experience the harm, with three examples of harms occurring to a person whilst they remain forever unaware of the harm; a trespasser on one’s land, an adulterous spouse, and libellous but secret descriptions of oneself.⁶⁰ Feinberg identifies the subject of such harms as the person who has died and the timing of the harm corresponding to the moment the living person acquired an interest that death or subsequent events defeats.

Naturally Feinberg is not without his critics. Earnest Partridge responding to an earlier version of Feinberg’s work keeps to a more Epicurean argument that says that the dead have no interests and are beyond either harm or benefit, however nevertheless we should respect the wishes of the dead, because we, the living, have an expectation that our wishes will be respected after our own death.⁶¹ Our life according to Partridges’ ‘social contract’ argument will go better if we respect the wishes of the dead, since to fail to do so would make our future orientated goals and interests a subject of such tenuous uncertainty

⁵⁸ *ibid* page 177 (italics as per Feinberg).

⁵⁹ *ibid* page 179.

⁶⁰ *ibid* page 180.

⁶¹ Partridge E. (1981) “Posthumous Interests and Posthumous Respect” *Ethics* 91 (January): pages 243-264.

we might decide not to invest our time into them. This situation would be worse for us and worse for society.⁶²

These are two possible defences for Gill's Respect of Wishes model of autonomy for the dead. I offer a third. In the introduction I made the claim that in NHBD we are treating the dying and unconscious intensive care patient as a means to another's end. I proposed that this violation of Kant's categorical imperative is more than just a failure in sentiment but a failure in the ethical treatment of the patient. This is a controversial claim. The irreversibly unconscious and the dead are not considered members of Kant's Kingdom of Ends, since they have lost the very rationality that Kant believes gives humanity value. Kant holds that by the very nature that we are rational beings, we have value, since only we, unlike animals, have autonomous wills and can choose ends. An end is determined by the will and is any desire or goal a rational being may hold. Since we place value on our own chosen ends, then by use of Kant's first categorical imperative, "Act only in accordance with that maxim through which you can at the same time will that it becomes a universal law,"⁶³ we must accept that other people, as end setting rational beings, also have value. The first categorical imperative can be considered as

⁶² Feinberg responded to Partridge in his 1984 "Harm to Others" article by arguing that Partridge dilutes our obligation to for example, keep a promise, into a general duty we owe to protecting the general trust in promises and neglects the claim of the promisee, regardless of whether the promisee has died. Feinberg J. (1993) "Harm to Others (Originally published in 1984)" in John Martin Fischer (Ed) *The Metaphysics of Death*. Stanford University Press: Stanford, pages 188-190.

⁶³ Kant I (1996) "The Groundwork of the Metaphysics of Morals (originally published in 1785)" as translated by Mary Gregor in *The Cambridge Edition of the Works of Immanuel Kant: Practical Philosophy*. Cambridge: Cambridge University Press: Section 4:421.

form without content. The content of the refashioned first categorical imperative is humanity and it gives us Kant's second categorical imperative, "So act that you use humanity, whether in your own person, or in the person of any other, always at the same time as an end, never merely as a means."⁶⁴ The most basic assumption the categorical imperatives are built on is that only the end setting of rational agents has moral worth, therefore everything else are means. A means is anything, which can be used to advance a chosen end. Therefore by Kant's reckoning, animals, small children, the dead and the unconscious and dying intensive care patient are means. Taking organs from the unconscious and dying intensive care patient without any form of consent would be a justifiable action since it serves the end setting of other rational agents and the dying patient is regarded as only a means, since the patient cannot be said to be capable of end-setting.

This strict reading of Kant, I believe, belies the subtlety of his philosophy. My hope is to sketch a potential argument based on Kant's philosophy where it might be possible to conclude that it would be wrong to regard the unconscious and dying intensive care patient and the dead, as mere means but instead they are best regarded as end-setting agents who have temporarily lost their rationality. This is the way we, the moral agent, should treat them even if the nature of their lost rationality is not temporary.

⁶⁴ *ibid* Section 4:429.

Kant says in his Groundwork, “A good will is not good because of what it effects or accomplishes, because of its fitness to attain some proposed end, but only because of its volition.”⁶⁵ A good will is good in itself and not dependent on the consequences. This is apparent in Kant’s still hotly debated example that it would be wrong to lie to a murderer who asked us whether a friend of ours whom he is pursuing has taken refuge in our house.⁶⁶ Kant’s example shows us the perspective we should adopt when deciding how to treat the potential NHB donor is our own and not that of the donors.

Following from this I offer two brief statements of defence. The first is based on potentiality or loss of potentiality for rationality. Allen Wood says:

“Strictly speaking, it is true that human beings deprived of their rational capacities are no longer “persons” (since they lack “humanity” in the technical Kantian sense). But if we respect the dignity of rational nature, we cannot regard these people as mere things. We have a duty to attempt to restore the rational capacities if they have been lost, and if the loss is due to the deliberate act of others, we must continue to treat the people as persons (in every way possible) if only to express our implacable opposition to what has been done to them.”⁶⁷

As part of our respect for the dignity of rational nature the loss of potentiality for rationality should be respected even if this is merely to express our own attitude to humanity. Likewise since we can easily imagine the NHB donor as a possible or potential person then so should we should treat them as a person.

Palle Yourgrau claims that Kant would subscribe to this belief because, “...

⁶⁵ *ibid* Section 4:394.

⁶⁶ Kant I (1996) “On a Supposed Right to Lie from Philanthropy (originally published in 1797)” as translated by Mary Gregor in *The Cambridge Edition of the Works of Immanuel Kant: Practical Philosophy*. Cambridge: Cambridge University Press: Section 8: 425.

⁶⁷ Wood A. (1999) “The Formula of Humanity as End in Itself” *Kant’s Ethical Thought*. Cambridge University Press, Cambridge, page 147. (Punctuation as per Wood)

merely possible people are *just like you and me*- except for their non-existence – and he [Kant] is at pains to insist that the existent and the non-existent do not constitute “special kinds of object.”⁶⁸

My second defence is to consider whether by treating the potential NHB donor as a means we create a contradiction such that we violate the first categorical imperative.⁶⁹ End setting is part of our rational nature. Since we are future orientated our end setting is also future orientated. Many people devote a lot of their energies for ends that can only occur after they are dead. This might be in financial preparations, personal letters left for loved ones, planned funeral arrangements or concerns over one’s legacy and reputation. I call this End Setting for the End. The end from a Kantian perspective is not necessarily death but any irreversible loss of rationality such that we are no longer capable of end setting. Could we will as a universal maxim that once we are no longer capable of end setting, our previous End Setting for the End should carry no moral weight with the living? This would mean, as per an example from Feinberg and Partridge that for Alfred Nobel, founder of the Nobel Prize, his executors should have had no moral requirement to carry through with his

⁶⁸ Yourgrau P. (1993) “The Dead (Originally published in 1987)” John Martin Fischer (Ed) *The Metaphysics of Death*. Stanford University Press: Stanford, page 148. (Punctuation as per Yourgrau)

⁶⁹ Kant identifies in his Groundwork two ways where willing a universalised maxim may lead to contradiction. Firstly there may be a contradiction in conception such that the maxim cannot even be thought without contradiction, and secondly, a contradiction in the will, such that willing the maxim would contradict itself. This second contradiction can be interpreted as willing something that reduces our moral agency since this reduces our value as rational agents, an impossible thing to will. Kant I (1996) “The Groundwork of the Metaphysics of Morals (originally published in 1785)” as translated by Mary Gregor in *The Cambridge Edition of the Works of Immanuel Kant: Practical Philosophy*. Cambridge: Cambridge University Press: Section 4:424 & Korsgaard C (1996) “Kant’s Formula of Universal Law” *Creating the Kingdom of Ends*. Cambridge University Press, Cambridge, page 77-8.

bequest.⁷⁰ Could we imagine a world where the living, do not follow through with the bequests of the dead? Certainly, therefore we can conclude there is no contradiction in conception. What would the consequence of such a world be? I would argue that our End Setting for the End would be in jeopardy. Since we seldom know when the end will come, all our future orientated end setting is also at risk. This would reduce our moral agency since it would limit our will to the end setting for the immediate alone. This I believe would represent a contradiction in will. From this Kantian defence I conclude that when considering the potential NHB donor it is right that we attempt to treat them as end setting agents to the best we can. The only way we can avoid treating the NHB donor as a means, is if the donor has chosen NHBD as an end.

When we come to organ donation it does not matter whether we accept Feinberg, Partridge or my Kantian justification, only that we reject the strict Epicurean argument, so that we should seek to respect the wishes of the dead. How then are we best to know the wishes of the dead with respect to organ donation and is maximizing the frequency of fulfilled wishes of the dead the only morally important action?

At present in the UK the wishes of the dead for organ donation are ascertained in two ways, firstly by looking for the deceased on the Organ Donor Register

⁷⁰ Feinberg J. (1993) "Harm to Others (Originally published in 1984)" in John Martin Fischer (Ed) *The Metaphysics of Death*. Stanford University Press: Stanford, page 176 & Partridge E. (1981) Posthumous Interests and Posthumous Respect. *Ethics* 91 (January) pages 259-61. Ironically Alfred Nobel died of cerebral haemorrhage and may today have been a candidate for NHBD.

and secondly by discussion with the family of the deceased, who it is believed are best likely to know the deceased's wishes regarding donation. I would be satisfied that if we *were* to treat the unconscious and dying intensive care patient as a Deceased Moral Agent, then these processes for ascertaining and respecting the wishes of the dead are satisfactory for HBD and NHBD.⁷¹ The new UK Human Tissues Act however raises fresh concerns about proposed practice. Under the UK Human Tissues Act (HTA), which comes in force from the 1st September 2006, theoretically at least, once a person is registered on the UK NHS Organ Donor Register, this will be taken as explicit consent for organ donation, such that the family will not be able to veto or overrule those wishes.⁷² I believe this Act and its associated codes of practice, is ethically flawed. Firstly, as I elucidated above, the UK NHS Organ Donor Register should be considered as intent not consent. Secondly I believe the Act makes the same mistake Gill does, in holding all wishes of the dead equal and for supposing, without adequate evidence, that organ donation is a strong held wish by those on the donor register.

Gill argues that the right action in our treatment of the dead is the one, which maximises our ability to fulfil the wishes of the dead.⁷³ For this reason he argues for an organ donation program based on presumed consent of the donor

⁷¹ Further justification for this view is given below.

⁷² The Human Tissue Authority (January 2006) "Code of Practice- Consent – Code 1" Human Tissue Authority. Points 45 & 47, page 15. & The Human Tissue Authority (January 2006) "Code of Practice – Donation of Organs, tissue and cells for transplantation – Code 2" Human Tissue Authority. Point 25, page 8. Explicitly at point 25, the use of the UK NHS Organ Donor Register for establishing consent for organ donation is made.

⁷³ Gill M. (2004) "Presumed Consent, Autonomy, and Organ Donation" *J Med Phil* 29(1): page 44.

since most people when opinion polled support organ donation, yet few, even when suitable, become organ donors. Gill holds it to be an equal moral wrong that those who wish to donate do not, as for those who do not wish to donate do.⁷⁴ As stated above I do not intend to argue either for or against presumed consent but instead I will apply Gill's Respect of Wishes model of autonomy to the UK NHS Organ Donor Register and the HTA changes. Firstly I will elucidate what I believe is right about the Donor Register and Gill's argument for respect of wishes and then I will argue for where I believe they are mistaken.

Is prior registration on a Donor Register a wish that we might subscribe to the dead? Certainly it was a voluntary act made in the past by a presumed competent adult, who must have taken at least some thought into registering in the first place. Compared to Gill's use of opinion polls to ascertain wishes it seems reasonable to conclude that we should consider registration on a Donor Register as a wish.

Is it a valid wish? A wish to donate could be considered valid if it was appropriate to fulfil, appropriately registered and appropriately informed. Wishes that are appropriate to fulfil are ones that generally do not harm the living. My colleague's mother may have asked, instead of her ashes being scattered in a duck pond, she wished for her ashes to be scattered on the moon. To fulfil such a wish is likely to result in harm to my colleague as he devotes

⁷⁴ *ibid* page 38.

all of his time and energy to his mother's wish at the expense of his own endeavours. Organ donation has a tangible benefit to the organ recipient and results in little discernable harm to others, often it is a comfort to grieving relatives, so that a wish to donate is a valid wish. Is it an appropriately registered wish? The UK NHS Organ Donor Register is a register but under the current on-line registration no witness or identification verification is required. I would question why when it comes to money and the estate of the deceased; a will must be witnessed but for the treatment of one's body after death no witness is required. In the UK a will becomes invalid after marriage and the terms of a will often try to predict and account for other life changing events such as the birth of children and the death of relatives; the Donor Register does none of these things.

Is the valid wish appropriately informed? I have already raised my concerns about the informing process of the UK NHS Donor Register. Despite the major change in the law with the introduction of the HTA there is still no plan by UK-Transplant to approach their 12 million registered individuals and inform them of this change.⁷⁵ However I concede that Gill is correct to surmise that our notions of autonomy are altered by death. Seeking informed consent from the dead is unlikely to yield guidance in deciding how best to treat the dead. The dead cannot be said to have a Best Interests, in the same way as a Living Moral Agent, and perhaps the best we might hold for is a prior expressed wish,

⁷⁵ Personal communication by a UK Donor Transplant Co-ordinator who preferred to remain anonymous.

such as being on a Donor Register or verbal instruction left with a relative. While it would be better if these prior wishes had been appropriately informed, we have no way of altering the informing process after death. The dead do not have the luxury of changing their minds and the best that we the living can do, is to try and respect their wishes, unless meeting the wishes of the dead represents a considerable harm to the living. Since I do not believe such considerable harm exists from organ donation, I would conclude that registration on the Donor Register is, whilst still areas of concern remain, a valid wish that should be respected. While intent is not consent, it is still a valid wish.

The mistake Gill and the HTA make is in holding all wishes of the dead equal and for supposing, without adequate evidence, that organ donation is a strong held wish by those on the donor register. Gill argues that the right moral action is the one that maximizes the frequency that wishes are respected. I wish that I had a promotion but I wish even more that I would not lose my job. Given a choice between losing my job and receiving no promotion, I wish for the latter. Which wish should be maximized? Gill holds it as an equal moral wrong that those who wish to donate their organs don't and those that don't do.⁷⁶ But this is to give every wish the same worth and even the individuals concerned might not concur. Those that don't want to donate might really not want to whilst those that do might be supportive but in general neutral about the wish being

⁷⁶ Gill M. (2004) "Presumed Consent, Autonomy, and Organ Donation" *J Med Phil* 29(1): page 38.

fulfilled. If we seek, as Gill does, to maximize wishes then we must surely seek only to maximize the occurrence of strong wishes. Strong wishes I would suggest are wishes, which if not fulfilled, are a source of harm. From Feinberg we can suggest that this harm can occur even from posthumous events. How do we know that organ donation is a strong wish of the deceased? I might have a valid wish as expressed on the Donor Register that after death my organs are donated but I wish even more that my loved ones are not made to suffer or have their grief increased by respecting this wish. Given a choice between emotional harm to my loved ones and physical harm to the organ recipient, in failing to receive my organs, I might wish that my loved ones be spared.⁷⁷ The Donor Register does not ask this question, it only asks if I wish to donate. The Donor Register provides no opportunity to state any personal stipulations apart from opposing the donation of particular organs. The Donor Register allows registration from 18 years and it is possible to go ones entire life without any further encouragement to reconsider or re-register one's choice. For some individuals organ donation is a strong wish but people register into a persuasive system for many reasons. The Donor Register cannot be used to conclude that a wish to donate is a strong wish. The mistake the HTA is making is to regard the UK NHS Organ Donor Register as representing

⁷⁷ Two responses might be made here. The first is that generally it has been shown that relatives emotionally gain from the donating process. While this may be empirically true I would argue that forcing donation because this will help the grieving process of the relatives is paternalistic and may not prove true when the gift giving nature of organ donation is lost. The second is that organ donation is a civil duty, in which case we are certainly not talking about respect of wishes and consent.

statements of strong wishes capable of trumping the feelings and knowledge of the family.

In summary if we regard the unconscious and dying intensive care patient as a Deceased Moral Agent then in NHBD, even though the donation process commences before organism death, our treatment toward the patient should morally resemble the treatment we currently give to heart beating organ donors. That is, we commence the grieving process and we attempt to respect the wishes of the dead when it comes to the donation of their organs. For a wish to be valid such that we should fulfil it even after death, it must be appropriate, preferably informed and a strong wish. Generally registration on the organ donor register acceptably fulfils the first two criteria. How are we to know the strong wishes of the dead when it comes to organ donation? Presence of the deceased on the donor register combined with the addition of family assent to organ donation, as has been the case until now, might make us feel more confident that in allowing organ donation we shall fulfil a strong wish of the deceased. Unfortunately the new HTA allows for presence of the deceased on the Donor Register to overrule family knowledge and feelings regarding donation. Gill might be correct that the right action is the one which maximises the frequency we respect wishes, provided I have argued the wishes are strong wishes, but the UK NHS Organ Donor Register does not allow us to make the conclusion that registration represents a strong wish of the deceased. For this reason the proposed UK controlled NHBD program is unethical, since

it will not gain *appropriate* consent for donation, even if we were to regard the unconscious and dying intensive care patient as dead already.

VI - Conclusion

Controlled NHBD offers tremendous opportunities it also offers new ethical challenges. It is not ethically identical to HBD. The donation procedure in NHBD must be part and parcel of the dying process due to the need to prevent warm ischaemia to the donor organs, whereas there is no necessity for it to be so in HBD. This represents a breach to the Dead Donor Rule. There are two legitimate responses to this contention. The first is that the Dead Donor Rule is not necessary provided the Consenting Donor Rule is satisfied as for a Living Moral Agent; and the second is that an unconscious and dying intensive care patient can be morally regarded as a Deceased Moral Agent, thereby satisfying the Dead Donor Rule. Accepting both of these responses at face value I explored their implications to the UK current and proposed controlled NHBD program with regard to satisfying the Consenting Donor Rule.

If we consider the potential NHB donor as a Living Moral Agent then we must accept the need for consent that meets criteria for informed consent. When informed consent cannot be given, the case in most controlled NHB donors, then we should act in the same way as we do for any other incompetent intensive care patient. I compared the current UK consenting process for NHBD, identical to that used for HBD, and compared it to a Hierarchy of Consent for Medical Interference. The consenting process failed because the Prior Expressed Informed Consent relied on the UK NHS Donor Register which does not inform, such that registration should be considered as intent

not consent; and it cannot be said it is in the patient's Best Interests to deviate from standard treatment and have their death altered for the sole benefit of others. The UK NHBD program is unethical even if we were to hold the Dead Donor Rule as unimportant.

Alternatively if we were to hold that an unconscious and dying intensive care patient be regarded as a Deceased Moral Agent, this would satisfy the Dead Donor Rule. I asked what obligations are owed to the dead and argued that it is right that we Respect the Wishes of the dead, Gill's model of autonomy for the dead. I rejected the Epicurean argument and argued using Feinberg, Partridge and Kant that we have an obligation to respect the wishes of the dead. The wishes we should respect are those that are appropriate, valid and strong. The current UK controlled NHBD program would respect, to a reasonable standard, the wishes of the dead, just as it does for HBD; however following the introduction of the UK HTA from September 2006, it would not. The HTA fails to discriminate strong wishes and will not satisfy the Consenting Donor Rule. The new law would make the proposed UK controlled NHBD program unethical.

What would make the UK controlled NHBD program ethical? The problems I identified are primarily problems in satisfying the Consenting Donor Rule. The UK NHS Organ Donor Register needs to change from being an instrument of persuasion to being a register of informed consent. The Register should

represent an individual's advanced directive for organ donation, requiring similar legal requirements to current advanced directives and encouraging individuals to re-express their declarations at regular but not burdensomely frequent intervals. It should allow individuals to express and store their Prior Expressed Informed Consent; their strong wish to, or not to, organ donate with any relevant stipulations; and the individual's attitude to NHBD and pre-mortem intervention. This may ethically allow in the UK some level of physical pre-mortem intervention to the overall benefit of the UK NHBD program. These changes would represent a good start.

For under the current and proposed UK controlled NHBD program the unconscious and dying intensive care patient is being treated as a means to an end. This is more than a failure of sentiment but a failure in ethics. In a hundred years time when necrodonation may have been superseded by new technologies, such as xeno and stem cell transplantation, the legacy we must not leave to future generations is that we devalued the worth of persons.

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Appendix A - Modified Maastricht Classification of Non-Heart Beating Donation

The types of patients who might be eligible for NHBD fall into five broad categories and are known internationally as the Modified Maastricht Classification of NHBD.⁷⁸

- Category I Dead on arrival
- Category II Unsuccessful resuscitation
- Category III Awaiting cardiac arrest**
- Category IV Cardiac arrest in a brain stem dead donor.
- Category V Unexpected cardiac arrest in a critically ill patient

Categories I, II, and V are uncontrolled whilst Category III, IV are controlled in the sense that the death is expected. Category IV is a rare frequency category. Typically Category III patients occur in intensive care environments. This usually following a treatment withdrawal decision, and allows time to organise and plan for donation, an advantage if warm ischaemic time is to be minimised.

⁷⁸ Intensive Care Society (2004) "Guidelines for Adult Organ and Tissue Donation" Pages 44-45.

Appendix B - 'Best interests' principle⁷⁹

“In deciding what options may be reasonably considered as being in the best interests of a patient who lacks capacity to decide, you should take into account:

- options for treatment or investigation which are clinically indicated;
- any evidence of the patient's previously expressed preferences, including an advance statement;
- your own and the health care team's knowledge of the patient's background, such as cultural, religious, or employment considerations;
- views about the patient's preferences given by a third party who may have other knowledge of the patient, for example the patient's partner, family, carer, tutor-dative (Scotland), or a person with parental responsibility;
- which option least restricts the patient's future choices, where more than one option (including non-treatment) seems reasonable in the patient's best interest.”

⁷⁹ United Kingdom General Medical Council (1998) “Seeking patients’ consent: the ethical considerations” *Guidance for Doctors - Consent*. Point 25.