

# BMA and NICE guidance on organ retrieval: neither misguided nor presumptuous

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**ABSTRACT – Organ donation from deceased donors should occur whenever appropriate: that is, when there is evidence, belief or understanding that donation was the stated wish of the potential donor or would be in accordance with their wishes, is lawful and in line with current guidelines and will not add further distress to the family. This is the underlying assumption of the British Medical Association (BMA) report, National Institute for Health and Clinical Excellence (NICE) Guideline and Welsh Government Assembly Report. For potential donors after circulatory death, it might be necessary to support the potential donor until the wishes of the person and their family are ascertained. Provided that such interventions are reasonable, explained and do not cause distress to the patient and their family, such measures are surely suitable and will also enable donation to occur when appropriate. Publication and adherence to guidelines that have clinical, legal and ethical validity will reassure the public. Organ donation not only improves the length and quality of life of recipients, but also saves resources for the NHS and provides benefit to the donor family.**

**KEY WORDS:** organ donation, presumed consent, deemed consent, opt-out, transplantation

## Introduction

*They that approve a private opinion, call it opinion, but they that dislike it, heresy: and yet heresy signifies no more than private opinion<sup>1</sup>*

Randall and Downie<sup>2</sup> argue that the National Institute for Health and Clinical Excellence (NICE) clinical guideline,<sup>3</sup> the British Medical Association (BMA) report<sup>4</sup> and a Welsh Government White Paper on opt-out for consent for transplantation<sup>5</sup> are ethically flawed. They suggest that the NICE and BMA recommendation that whenever there is intention to withdraw life-sustaining treatment and death is expected, patients should be stabilised to assess for donation is contrary to a patient's best interests, the principles of mental capacity legislation and the current criteria for accessing intensive care units (ICUs). They claim that the language of all three proposals is manipulative, and suggest that patient trust will be undermined because the doctor's attention must move from the interests of the patient to those of the unknown organ

recipients. I believe that they are mistaken and that all three approaches have been developed in the best interests of both patients and their families, and are ethically and legally sound.

## Background

Despite the many advances in the understanding, prevention and treatment of many diseases, the number of people who would benefit from solid organ transplantation has increased and exceeds the number of grafts available. Transplantation is effective in improving both the length and quality of life of transplant recipients, as well as saving costs to the NHS.<sup>6</sup> Solid organs can be donated by living or deceased donors: the latter might have died a neurological (donation after brain death (DBD)) or a circulatory (donation after circulatory death (DCD)) death. Although both the number of organ donors and the number of solid organ transplants in the UK has increased over the past 5 years, the need still exceeds availability. The increase in donors and transplants has been primarily from living and DCD donors.

Both legal and ethical issues surrounding donation and transplantation have rightly received, and continue to attract, much attention from all interested parties and the general public. Clarity and transparency are essential to ensure that the public retains full confidence in the delivery of healthcare. Therefore, there is a need for the provision of clear guidance for those involved in the care of the potential donor, as well as for those involved in other areas of donation and transplantation. Several documents have been issued over many years to clarify the issues and these come from, among others, lawmakers, regulators of healthcare delivery, and the statutory, clinical, scientific, professional and patient bodies. Individuals will also wish to express their own views.

Policy and guidance documents must be in the public domain so that all can be reassured that practice is appropriate. Not only will social and clinical practice change with time, but public perception and opinion will also evolve and might vary between individuals, groups and societies.

## Principles of organ donation

There are some clear principles that all those involved in donation (including possible and potential donation) and transplantation fully endorse:

- the over-riding aim of the clinicians is to save the life of the patient;
- only when it is clear and agreed that life-saving measures are futile or inappropriate should organ donation be considered;

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- those involved in donation or transplantation should not be involved in confirming death or deciding that further treatment to save life is futile; and
- organ donation should proceed if appropriate.

Organ donation is appropriate in those circumstances where:

- there is evidence, belief or understanding that donation was the stated wish of the potential donor or would be in accordance with their wishes;
- donation and retrieval is lawful and in line with current guidelines; and
- donation will not add further distress to the family.

### Some current guidelines

The accompanying article *Misguided presumptions* questions some of the assumptions made in recent documents, including the NICE guideline<sup>3</sup> (*Organ donation for transplantation*), the report from the BMA (*Building on Progress: where next for organ donation in the UK?*)<sup>4</sup> and the proposals from the Welsh Government for an opt-out system for consent.<sup>5</sup>

It is worth noting that the BMA Medical Ethics Committee, which generated the BMA report, included ethicists and experts in law, and that none of the medical members was a transplant clinician. The NICE Guideline development group comprised nine members who were either non-transplant clinicians or lay members, in addition to one regional manager for NHS Blood and Transplant (a clinician responsible for organ donation), an intensive care consultant, who was also national clinical lead for organ donation, and a co-opted transplant surgeon. There was no expert in medical ethics or law, although the report confirms that 'legal advice was sought and incorporated during the development of the guideline' and details are given in the text. The group was overseen by an independent guideline review panel that did not include a transplant clinician but did include a lead in clinical ethics. Thus, these guidelines were produced with expert clinical advice, but primarily by lay members with appropriate ethical and legal support. It should be noted that the Department of Health (DoH) and the Welsh Assembly Government have issued a document outlining their view of the legal position that can lawfully be taken before death to support DCD donation.<sup>7</sup>

The NICE document states that 'there are steps that health-care professionals may need to take before the death of the patient if donation is to proceed' and makes several recommendations. These include: clinically stabilising the patient in an appropriate critical care environment while the assessment for donation is performed (recommendation 1.1.6) and the further recommendation (1.1.7) that provided that delay is in the patient's overall best interests, life-sustaining treatment should not be withdrawn or limited until the patient's wishes explored and the potential to donate assessed. The Mental Capacity Act requires that best interest decisions take into account the 'past and present wishes' of the patient where these can be ascertained. This can be done in a few minutes when the person has

recorded his/her wishes on the Organ Donor Register (ODR), but clinicians will normally also involve the family.

Given that these recommendations are supported by both legal (from the DoH) and professional advice (from the Intensive Care Society and the General Medical Council), is this approach so unreasonable? Are additional interventions associated with stabilisation, such as administration of oxygen, giving intravenous fluids or even taking blood for diagnostic testing, harmful or intrusive? Stabilisation does not involve inhumane treatments. The Human Tissue Authority<sup>8</sup> has stated that 'the taking and storage of blood samples is a necessary action to ensure that the preserved organ can be used for transplantation in cases where consent for donation is given later (paragraph 131) and (paragraph 123) that 'there may be occasions when steps need to be taken to preserve the viability of an organ, while it is being established if a decision on consent has been, or will be, made'. Pre-emptive ventilation is not legal in the UK.

Families are kept informed as to what is being done to the patient as well as the reasons underlying any interventions. It might well be appropriate to move the potential donor from an emergency department or ward to a side-room or elsewhere to provide the care not only to the patient, but also to the family in an appropriate setting. The specialist nurses in organ donation (SNODs), as all other trained personnel, recognise not only the clinical obligation to support the family, but also the importance in doing so to promote organ donation. One family's bad experience will not only harm them, but might also adversely impact on the national support for donation.

The review<sup>2</sup> also suggests that it is a poor use of a scarce resource to use one ICU bed for a dying person solely for the purposes of donation. This again shows a misunderstanding: potential donors can be nursed in ICU beds certainly, but can also be appropriately nursed in side-wards. Furthermore, to use a scarce resource to care for a person who might donate and so save up to six lives, seems a good investment and many studies have shown that kidney transplantation saves the NHS considerable resources.<sup>6</sup>

### Consent, presumed consent or opt-out?

In practice, clinicians use registration on the ODR as an indication of the person's wishes to donate: the family's views are also taken fully into account. Although surgeons can legally retrieve organs contrary to the wishes of the family if the patient had made his/her wishes explicit, this is not done. In the UK, the families overrode the stated wishes on the ODR of the patient in 8% of 1,058 potential DBD donors and 24% of 1,359 DCD donors.

An opt-out approach has been adopted in many European countries without problems.<sup>9</sup> It is beyond the scope of this article to discuss the ethical pros and cons of opt-out: suffice to say that a democratically elected government, such as the Welsh Assembly Government, must surely have a right to introduce such legislation and so this approach will have moral as well as legal authority.

## Manipulative language?

There is a fine line between inference and implication. Both anecdote and research show that those families who have supported donation derive comfort and consolation from the donation and the knowledge that their tragedy has meant life for others.<sup>10,11</sup> Therefore, it is not unreasonable to emphasise the benefits of donation to both clinicians and families.

## Social attitudes

Social attitudes are, of course, important and clinicians do recognise the duty to treat people, before and after death, with dignity and respect. Social attitudes vary between individuals, cultures, groups and over time, and all those involved in health-care should be sensitive and aware of these issues.

I would argue that the outrage felt by the families of children involved with the scandal at the Royal Liverpool Children's Hospital was not related to the removal of organs *per se* but that this was done without consent or knowledge.<sup>12</sup> Those involved in requesting consent fully appreciate the need to inform the family as to what is involved and to treat the donor with respect at all times.

## Declaration of interest

As a liver physician, working in the field of liver transplantation for over 30 years, and as associate medical director for Organ Donation and Transplantation, I have first-hand experience of the huge benefits that transplantation brings not only to patients with end-organ disease, but also their families and friends. However, I also recognise the benefits that donation brings to the donor families. I accept that this experience will affect my views.

## Conclusions

All clinicians working in donation and transplantation fully appreciate that transplantation is dependent on organ donation and that organ donation will not occur unless the public have full confidence in the integrity of the system and the principles outlined above. Therefore, it would be more than foolish, as well as unprofessional and unethical, to deviate from those principles.

Clinicians should welcome authoritative and expert advice as how best to ensure that organ donation occurs whenever appropriate and in a manner that that is both ethical and legal and provides comfort and support for all involved. Transparency and openness will enhance the doctor–patient relationship, not harm it. Whatever ‘the State’ might legislate, those involved in donation

and transplantation do not assume that every individual should donate organs after their death; they do not approach families where the potential donor or their family have indicated that they would not support donation but those clinicians do, and should, allow potential donors the opportunity to donate whenever appropriate.

The purpose of the guidance from the BMA and from NICE is not to increase donation at all costs but rather to ensure that the wishes of those who wish to donate are followed whenever it is appropriate. Individuals have a right to disagree with published guidance and have such discordant views considered but those views need to be placed in context and responded to as such.

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