

## **Inquiry into Presumed Consent for Organ Donation by the Health, Wellbeing and Local Government Committee, National Assembly for Wales: A Response by the National Secular Society 2008**

The National Secular Society takes the position that donation of organs by consenting adult individuals either while they are living or after death is entirely a matter for personal decision.

However, there are certain concerns raised by the proposed opt-out (presumed consent) system relating to possible religious objections. These concerns apply whether the new system is adopted only in Wales or in the UK as a whole.

The UK has one of the lowest donor rates in Europe, at only 35 per million of the population. In 2006/7, 3000 patients had transplants but 1000 died waiting. The waiting list is currently nearly 7700, growing at around 8% pa. Given these statistics, the NSS is concerned to minimize reasons for failing to donate or blocking donations that are based on misperceptions of religion.<sup>1</sup>

### **Hard and Soft Systems of Consent**

There are two proposed methods of applying the opt-out process. The first is the so-called 'hard system' whereby if the donor does not opt out, organs will be harvested. The second is the 'soft system of consent'. Under this system, relatives would have the final say, whatever the wishes of the donor. This is the approach currently favoured by the BMA.

It is possible that a donor may have changed his or her mind and expressed this to relatives but not registered the change. The concern of the NSS is that relatives may object for religious reasons based on their beliefs not held by the donor.

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<sup>1</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_082122](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082122)

Studies show that while around 90% of the population support organ donation, only around 24% have currently signed up to be a donor. However, there is around a 40% refusal rate by relatives, so the effective donor pool is reduced to less than 15% of the population. The potential for relatives to refuse at the last moment for their own reasons is therefore a serious concern.<sup>2</sup>

### **Religious objections to donation**

Within black and ethnic minority (BME) groups, there are common myths that are known to affect donation rates, such as assumed religious objections: *'Key barriers to donation among black and Asian communities include assumed cultural or religious objections to donation, confusion about who can donate and receive organs, a reluctance to discuss death, and fear of bodily disfigurement.'*<sup>3</sup>

While BME groups represent only 8% of the population, they are 3-4 times more likely to need a kidney transplant. In 2003-4, only 3% of all donors came from BME groups.<sup>4</sup>

People from African-Caribbean and south Asian communities are three times more likely to suffer from kidney failure due to diet and lifestyle factors, as well as increased susceptibility to diabetes and high blood pressure, which can cause organ failure.

Almost 1,800 currently need a transplant, and their chances of success are greater if they can be matched with a donor from the same ethnic origin. Transplant patients from these communities typically wait twice as long as others for a suitable donor to become available. At the end of 2006 there were 1,798 black and Asian patients actively listed for an organ transplant, a 17% increase on the 2005 year-end figure. The majority needed a kidney transplant. Black people wait an average of 1,389 days for a kidney transplant and Asian people an average of 1,496 days. In contrast, white patients wait an average of 722 days.<sup>5</sup>

*The NSS of course recognises that it is not solely people from BME groups who may have religious objections, but this group is particularly affected by a combination of high need, low donor rates and misconceptions about donations.*

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<sup>2</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_082122](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082122)

<sup>3</sup> (Connect Research and Consultancy Ltd for UK Transplant, April 2006.)

<sup>4</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_082122](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082122)

<sup>5</sup> [http://www.uktransplant.org.uk/ukt/newsroom/news\\_releases/article.jsp?releaseld=178](http://www.uktransplant.org.uk/ukt/newsroom/news_releases/article.jsp?releaseld=178)[http://www.uktransplant.org.uk/ukt/newsroom/news\\_releases/article.jsp?releaseld=178](http://www.uktransplant.org.uk/ukt/newsroom/news_releases/article.jsp?releaseld=178)

## **Misconceptions about donation**

In fact, none of the major faiths practised in the UK forbid donation. The UK Transplant Campaign – titled *Can we count on you?* – has received backing from Christian, Muslim, Jewish, Hindu and Sikh leaders, who recognise that more BME organ donors are needed to increase the number of life-saving transplants for people from these communities.<sup>6</sup>

## **Potential for refusal by relatives**

The NSS's concern is that if the soft option is adopted, relatives of the donor may prevent the donation happening despite campaigns by religious leaders and donation organisations. In many cases, the donor may have abandoned the religion of his or her family. Alternatively, while still belonging to the religious community, he or she may have an attitude towards donation that is not based on a misperception of religious teachings.

## **Recommendations**

The NSS would recommend that:

1. Given the shortage of donors from BME groups and the need for donations, the NSS would recommend that the 'hard option' be adopted so that the donors' wishes will be respected.
2. In order to facilitate the hard option working in practice, potential donors should be given sufficient information both by donation organisations and by their community leaders that will allow them to discuss matters sensitively with their families in advance, to minimize the chance of a donation being prevented. Advance discussion would pre-empt distress to families at the time of bereavement.
3. Religious leaders in local BME communities should publicize more actively the fact that they are not against donation and make information easily available to their communities.

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<sup>6</sup>[http://www.uktransplant.org.uk/ukt/newsroom/news\\_releases/article.jsp?releaseId=178](http://www.uktransplant.org.uk/ukt/newsroom/news_releases/article.jsp?releaseId=178)[http://www.uktransplant.org.uk/ukt/newsroom/news\\_releases/article.jsp?releaseId=178](http://www.uktransplant.org.uk/ukt/newsroom/news_releases/article.jsp?releaseId=178)