Editorials

Organ donation in the UK:

how general practice can help

Solid organ transplantation not only dramatically improves the length and quality of life of the recipients but also saves the NHS money.[1,2] Organs routinely transplanted include heart, lung, liver, pancreas, and bowel but other organs that may be transplanted include thymus, hand, face, leg, abdominal wall, and uterus. The last two decades have seen major changes in organ transplantation: developments in surgery, anaesthesia, interventional radiology, microbiology, and pharmacology have transformed what many still today believe is a high intensity, high risk procedure with a high mortality to a routine procedure with low morbidity and a high long-term success rate. As the number of patients undergoing and surviving transplantation increases, GPs will see increasing numbers. However, transplantation activity is limited by donor availability.

TYPES OF ORGAN DONATION

Organ donors may be living or deceased. Living organ donation is regulated across the UK by the Human Tissue Authority which ensures that donation is done ethically, legally, and without financial or other inducement. Most living donations are directed to a named recipient (usually a family member or close friend) but we are seeing a small but increasing number of altruistic donors who donate to strangers. Living donation is not devoid of risk to the donor: the risk of death for a kidney donor is of the order of 1 in 4000 but for a living liver donor, the risk of death is about 1 in 250. Deceased donation may occur after brain death (DBD; previously known as heart beating donors) or after circulatory death (DCD).

ORGAN DONATION: THE PAST DECADE

A decade ago, the UK was very firmly in the lower ranking for organ donation (with donor rates of 12.0 per million population (pmp) in 2003 (Figure 1). The UK government set up the Organ Donation Task Force which made a number of recommendations which, if implemented in full, was predicted to result in a 50% increase in organ donors in the 5 years ending April 2013. To many people's surprise, this target was reached: just. The UK now has a donation rate of 18.3 pmp, but still remains outside the top league.

In September 2013, Royal Assent was given to the Human Transplant (Wales) Act which paves the way for a system of deemed consent to be introduced in Wales. This initiative, which will take full effect in late 2015, follows widespread consultation and discussion, and will include an active and far-reaching information campaign and, no doubt, many patients will wish to seek advice from their family doctor.

GIVEN THE INCREASE IN DONATION, WHAT THEN IS THE PROBLEM?

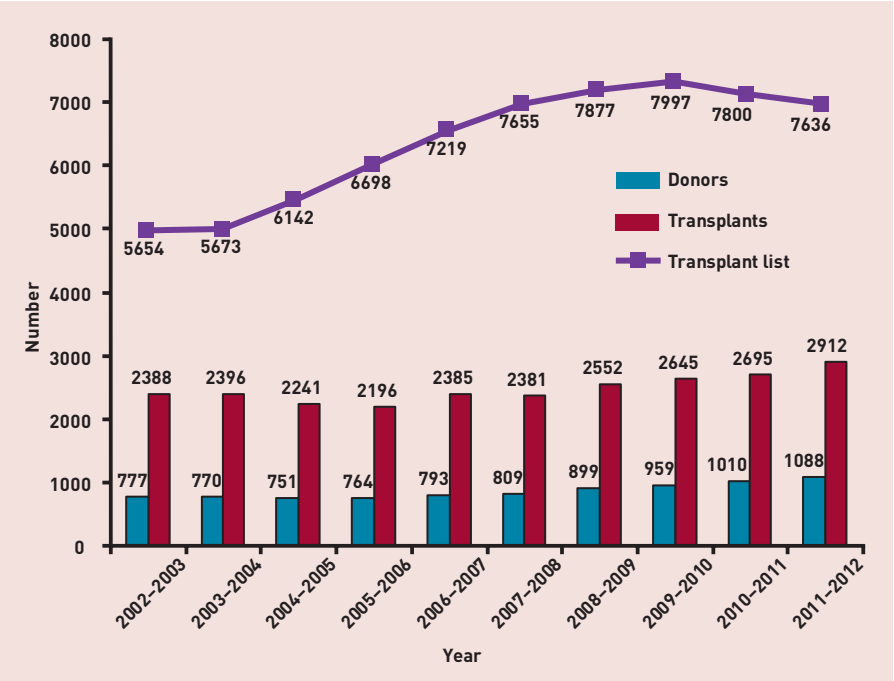
The increase in organ donors has not been matched by an increase in transplants because nearly all the increase has been from DCD donors where there are fewer organs suitable for transplantation (mean of 2.5 for DCD compared to 3.9 for DBD donor) as the mode of death renders some organs ischaemic and so unsuitable for transplantation. Furthermore, the potential donor pool is shrinking as death rates fall and those donors who do donate are older and heavier; both factors reducing the number of suitable organs that can be retrieved. Thus, the mortality of those on the national waiting list remains around 15–20% for those awaiting a heart, lung, or liver.

WHAT IS THE SOLUTION?

Without organ donation there can be no transplantation. Although the number of people joining the organ donor register has now reached over 19 million, the UK has the second highest rate of refusal for donation in Europe: although surveys proudly state that over 80% of the population support organ donation, nearly 45% refuse consent when the opportunity actually arises.[3] This rate has barely changed in the past decade. Reasons for refusal are complex and poorly understood, despite considerable research effort.

GPs are in an excellent position to help increase organ donation but do they have an obligation to do this? Do physicians have a moral obligation to educate patients about donation and discuss this option? Ladin and Hanto argue they do, 'insofar as informing patients about organ donation fulfils their duties of beneficence, respect for autonomy, and justice'.[4] Furthermore, they argued that promoting organ donation and altruistic behaviour, in a manner that recognises the essential nature of organ donation as a voluntary gift, and is consistent with the patient's worldview is an

Figure 1. UK donors, transplants, and numbers waiting at end of year (2002–2003 to 2011–2012) (data from NHS Blood and Transplant [NHSBT].[3] Reproduced with permission from NHSBT].



integral part of health promotion.

Any reader of this editorial will know that GPs are facing an increasing workload without a corresponding increase in resource. A recent survey of 200 GPs in Ireland[5] reported that around one-third only carried information about organ donation or provided organ donor cards, fewer than 1 in 20 ever raised donation with patients or families, and only one-third felt informed enough to discuss organ donation. Broadly similar results were reported in the US showing that few GPs ever discussed organ donation.[6] Those who had received specific training and those who ever discussed end-of-life care were more likely to discuss organ donation but evidence suggests that the doctor's attitude to and support for organ donation is more important than their knowledge.[7]

There are many opportunities in primary care to raise the possibility of organ donation: whether at registration, by posters and leaflets or videos in the waiting room, or by word of mouth in consultations: these are all simple and effective ways of encouraging discussion about organ donation. Given the perceived dissatisfaction with many Quality and Outcomes Framework (QOF) indicators,[8] NICE should be encouraged to consider replacing at least some of them with an evidence-based QOF indicator[9] aimed at promoting organ donation. Bearing in mind that organ donation is much more likely when the family of a potential donor is aware of their wishes, the frequent occasions in primary care when more than one member of the same family who are able to consider organ donation are seen together, the indicator might be more effectively targeted at 'starting the discussion' rather than just 'ticking the donor box'.

WAYS IN WHICH GPs CAN HELP DONATION

Increase awareness and debate

It is perhaps not surprising that some families, when asked for consent (or authorisation in Scotland) at a time of sudden and unexpected loss of a close family member will refuse consent, especially if this possibility has not been raised before. Fear of mutilation, uncertainty over the wishes of the person, concern that care will be less if the person is known to wish to be an organ donor in the event of their death, perceived religious barriers, and the feeling that the person has suffered enough are some of the commoner reasons given. These fears and misapprehensions need to be placed in context: the major religions all support organ donation so concerns are more cultural rather than religious. The donor continues to be treated with dignity and respect and organ donation is considered only when death has been confirmed or further treatment confirmed as futile and the donation team are and must be seen to remain independent of the clinical team. Greater discussion in life will ensure that the wishes of the deceased are known beforehand and so make it easier for the family to ensure the wishes of the deceased can be fulfilled. Our own data show that consent is very much more likely when the family are aware of the wishes of the potential donor.

Emphasise the benefits to the donor family of organ donation

Organ donation benefits not just the recipients but also the donor family. While less than 5% of donor families regret donation, around 40% of those who refused consent, later regret their decision. Donor families get great solace from the knowledge that from their personal tragedy has come life for up to six people, this translates, in part, into less need for bereavement support.

Dispel myths

In addition to dispelling the myths about donation outlined above, doctors should be familiar with the realities of donation. Donation of organs can be considered in anyone aged <75 years. Contraindications are few and include untreated infection, disseminated malignancy and Creutzfeldt-Jakob disease. Chronic infection with HIV, hepatitis B or C virus are no longer absolute contraindications.

In conclusion, organ transplantation is life-saving and enhancing as well as cost efficient. Without organ donation, there can be no transplantation and many lives are needlessly wasted as opportunities for organ donation are lost. GPs can play a major role in increasing awareness, dispelling myths and so support organ donation whenever it is possible and appropriate.

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Provenance
Commissioned; not externally peer reviewed.

DOI: 10.3399/bjgp13X673577

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