



The Voice of Transplantation in the UK

Directed Altruistic Organ Donation



Compiled by a Working Party of
The British Transplantation Society
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British Transplantation Society Guidelines



British Transplantation Society (BTS)

Guidelines for Directed Altruistic Organ Donation

Background

These guidelines have been drafted in response to the publication of the revised guidance and legal framework for living donation from the Human Tissue Authority (HTA) in September 2012¹, which confirms the legal position with respect to directed altruistic donation (DAD).

The HTA framework describes a spectrum of relationships that constitute directed altruism and defines two categories:

1. Genetic relationship and no established emotional relationship (e.g. donors living overseas who have not seen their potential recipient for many years; relative with whom there has been no contact previously)
2. No pre-existing relationship between donor and recipient prior to the identification of the recipient's need for a transplant (i.e. contact through social networking or media campaigns e.g. facebook, bespoke websites, local newspapers).

Within the Human Tissue Acts (HT Acts)², the HTA can give legal approval for DAD cases to proceed if the Authority is satisfied that two requirements are met:

- a) there is no evidence of coercion of the donor
- b) there is no evidence of reward for the donor

In order to address the potential/perceived increased risk of coercion or reward in DAD, the HTA has introduced a requirement for enhanced independent assessment (IA) for all cases of directed altruistic donation and has provided additional training for a selected group of independent assessors to ensure that this is provided within each transplanting centre.

The recommendations in this guidance reflect the outcome of discussions and debate within the following BTS Forums/Committees:

BTS Living Donor Forum, November 2012
BTS Ethics Symposium, December 2012
BTS Ethics Committee, case discussion 2012/2014

Purpose

DAD is a challenging and controversial area in living donor transplantation practice but, as public awareness has increased, more potential donors and recipients are wishing to explore this option. In order for the clinical community to respond consistently and appropriately to requests for DAD, an agreed approach and framework for such cases is needed.

These guidelines have been produced as an addendum to the BTS/RA 'UK Guidelines for Living Donor Kidney Transplantation', 3rd Edition, May 2011³ but are also applicable to living donation of other organs (e.g. liver). They outline the key principles and practices associated with DAD using the existing Guidelines as a prerequisite in the assessment of the prospective donor.

This is the first attempt to define practice guidelines for DAD. The recommendations proposed in this document will be reviewed in 2 years but can be revised earlier if required.

Recommendations

1. To maximise equity of access to living donor transplantation, non-directed altruistic donation (NDAD) is the preferred option in category 2 cases i.e. where there is no pre-existing relationship between donor and recipient prior to the recipient's need for a transplant. In such cases, NDAD must be discussed with all potential directed altruistic donors at the time of referral for assessment. If clinically appropriate, NDAD should also be explored in cases where directed altruistic donation (DAD) does not proceed (e.g. multiple donors for a single recipient). A directed altruistic donor may be registered with a specified recipient within the paired/pooled donation scheme provided that the donor is fully aware of the commitment that is required to minimise risk of identified matches not proceeding to transplantation within the scheme.
2. All potential donors and recipients considering DAD should be provided with generic information to inform their choices. Information is available through NHS Blood and Transplant (NHSBT) at www.organdonation.nhs.uk.
3. A DAD can only be directed to an identified recipient but is not permitted to a particular group of potential recipients on the national waiting list (e.g. by age, ethnicity, gender). This is consistent with the principles of distributive justice that underpin the national allocation schemes for both deceased donation (DD) and NDAD.
4. Donor and/or recipient referrals for DAD from outside the UK will only be accepted for living donor assessment if they are category 1 cases i.e. genetic relationship with no established emotional relationship (e.g. estranged family member due to geographical location).¹ Category 2 donors, where there is no previous relationship with the recipient prior to identifying his/her need for a transplant, will not be accepted into the living donor programme. This is due to the complexity and increased risk of non-proceeding transplants from donors who are resident overseas and is consistent with current policy for NDAD in living donor kidney transplantation (LDKT).
5. DAD donor referrals that arise from paid advertising or via websites where potential transplant recipients pay a fee to register their need for an organ transplant will not be accepted for living donor assessment. This is due to a lack of clarity in the motivation for donation in these cases and the associated difficulty of ruling out coercion and/or reward.
6. Provided that payment has not been made for advertising (see recommendation 5), DAD donor referrals that arise from advertising and/or awareness campaigns via social networking sites or media stories (e.g. human interest stories posted on facebook, twitter, local or national news) will be considered for living donor assessment.
7. To minimize the potential risk of coercion, donor referrals where the potential donor has spontaneously initiated contact with the transplant centre or potential recipient are considered preferable to those where the recipient

appears to be initiating the process. Careful consideration must be given to all DAD cases to ensure that the principle of donor voluntariness is upheld.

8. Potential donors for DAD can be assessed and the donation surgery performed either in their local transplant centre or in the same centre as the recipient (if they are not the same), depending upon donor and recipient preference and at the discretion of the donating and recipient centres.
9. Donor referrals may originate from various sources and multiple donors may volunteer to donate to a single recipient. Contact from the donor will either be via the potential recipient or directly to a transplant centre. To avoid multiple, simultaneous donor assessments being performed, the route of referral and identity of the recipient must be established as soon as possible and the recipient centre informed. The recipient centre should decide in conjunction with the donating centre/s (if relevant) which donor is assessed first and where this is performed. Where clinically appropriate, declined referrals should be referred for NDAD (see recommendation 1).
10. For the purposes of Independent Assessment (IA), the HTA assumes that the donor and recipient are known to one another in DAD and that IA interviews will be performed together and separately as in all cases of directed donation. Exceptions will be considered by the HTA on an individual basis¹. Preference for anonymity for both donor and recipient must be established at the outset so that each can be appropriately counselled and agrees to the terms of the donation and transplantation.
11. Assessment of the directed altruistic donor should be performed according to the recommendations specified in existing UK Guidelines for all directed and non-directed kidney donors³. Where organ specific UK Guidelines do not currently exist, the same principles should be applied (e.g. in liver) and all aspects of potential coercion and/or reward must be carefully considered. Mental health assessment is considered clinically mandatory. The HTA requires enhanced IA by an assessor who has received additional training prior to referral to an HTA panel¹.
12. For further advice and guidance on ethical aspects of DAD and/or to discuss specific cases, the BTS Ethics Committee can be contacted on ethics@bts.org.uk

References

1. Human Tissue Authority, Guidance to Transplant Teams and Independent Assessors, September 2012.
[http://www.hta.gov.uk/db/documents/Guidance to Transplant Teams and Independent Assessors 201209105840.pdf](http://www.hta.gov.uk/db/documents/Guidance%20to%20Transplant%20Teams%20and%20Independent%20Assessors%20201209105840.pdf)
2. Human Tissue Act 2004 and Human Tissue (Scotland) Act 2006
<http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/legislation/humantissueact.cfm>
3. British Transplantation/Renal Association, UK Guidelines for Living Donor Kidney Transplantation, 3rd Edition, May 2011
<http://www.bts.org.uk/Documents/Guidelines/Active/UK%20Guidelines%20for%20Living%20Donor%20Kidney%20July%202011.pdf>