

NHS BLOOD AND TRANSPLANT ORGAN DONATION AND TRANSPLANTATION

BRITISH TRANSPLANTATION SOCIETY

GUIDANCE FOR THE TRANSFER OF NHS PATIENTS WHO ARE CANDIDATES OR LISTED FOR SOLID ORGAN TRANSPLANTS IN THE UK

1. Background

NHS patients who are being assessed for solid organ transplants or who are registered on the UK National Transplant List may wish or need to be transferred to other transplant centres. There are many possible reasons for transfer which may include paediatric patients reaching the age and development where follow-up at an adult centre is more appropriate, change of domicile or, rarely, loss of confidence in the centre where they are being followed. Patients awaiting a solid organ transplant from a deceased donor may not be listed at more than one centre.

2. Purpose of guidelines

The purpose of these guidelines is to facilitate transfer of care and outline the roles and responsibilities of those involved.

3. Principles

3.1 Patient choice

Patients have the right to ask to be referred to the designated transplant centre of their choice for their transplant assessment, listing, monitoring while on the list, transplant operation and follow-up and to request a change of care at any stage of the pathway. However, patients with end-stage kidney disease may require to have dialysis in their local or satellite centre and to have their transplant assessment in another hospital and transplantation centre. In addition, patients with multiple medical needs under different teams may require to be seen at different hospitals for various aspects of their clinical care due to local experience.

3.1.1 The initial referral to the transplant centre is usually from the secondary care or tertiary care paediatric centre but may be from other transplant centres, the primary care doctor or others.

3.1.2 There are several possible reasons for requesting change: these include a need to change when follow-up in a paediatric centre is no longer appropriate, change in residence or, rarely, loss of confidence in the centre.

3.1.3 Incapacity: Where the patient is unable, because of medical or other reasons, to make a decision for themselves, the decision must be made by the responsible carer although the wishes of the patient, where known, should be respected.

3.2 Responsibility of care

3.2.1 Optimal care of patients both before and after transplantation is provided by a team which will consist not only of surgeons and physicians, but also many others, including nurses, pharmacists, anaesthetists, physiotherapists, dieticians and members of the psychosocial team (such as social workers, psychologists, family therapists, counsellors and youth workers). Although the accountable person may be the named Consultant Clinician, the team carry the responsibility to ensure that the change of care is done in accordance with the wishes of the patient, their family/carers and as smoothly and safely as possible.

Transfer of children to adolescent or adult services is normally a planned transition and the timing will depend on many factors, especially the medical and personal needs of the individual. Therefore, the transition may begin at any age between 13 and 18 years of age. Many children's hospitals will have designated transition co-ordinators who will support the patient and family during this transition process and will liaise with the accepting hospital.

3.2.2 Re-listing at new centre

It must not be assumed that the accepting centre will automatically accept the patient for listing at their centre. There may be some specialised transplantation services which are not offered at all centres, such as requirement of treatment to reduce antibodies for blood group (ABO) or HLA incompatibility.

3.2.2.1 The named Consultant Physician and Surgeon must satisfy him/herself that transplantation is appropriate for that individual and has the right and duty not to accept a patient for care at that centre if they believe that this is the clinical, moral and ethical approach that is in the patient's interest.

3.2.2.1.1 Refusal to accept a listed patient for medical reasons may be justified in a small number of situations which may include:

- change in the clinical status of the patient (such as deterioration so that the transplant would be futile or development of cancer)
- change in the behaviour of the patient (such as non-compliance with treatment so that the transplant would be futile or return to alcohol or other drug abuse, despite full support)
- improvement in condition so transplant is no longer needed at that time
- clinical conditions which the accepting team feel is outside their skill (such as the refusal to accept blood or blood products)

3.2.3 Where a clinician believes that they should not accept a patient listed for transplantation onto their list, they should:

- Discuss and agree this course of action at a multi-disciplinary team meeting
- record the reasons for this course of action
- Inform the patient and family/guardian where appropriate of their decision and reasons
- Inform the referring team of their decision and reasons
- Collaborate with the patient, the referring team and colleagues in other transplant centres to seek a second opinion

3.3 Responsibilities

3.3.1 Referring Clinical Team

Those clinicians at the referral centre have an obligation to agree to all reasonable requests by the patient and should not obstruct requests to change care. This includes:

- Ensuring the patient (and where appropriate family member or legal guardian) are in full agreement with the proposed change, understands the

reasons for the change and the different approach to management (where appropriate)

- Making the referral to an appropriate clinician in a timely fashion
- Ensuring all relevant details are provided when requesting change of care
- Identifying any special needs required by the patient and family
- Maintaining care until the accepting clinician has accepted care of the patient
- Ensuring the patient is not, and does not feel, prejudiced by the request to change care
- Making available copies of all relevant clinical and other records, including all investigations and other material such as histological specimens.
- The referring team should not become involved in the management of the patient once care has been transferred to another team without specific agreement as multiple teams having responsibility for the same aspect of care may lead to patient harm.

3.3.2 Accepting Clinician

It is good practice for the patient and family/carers to meet the accepting team before formal handover of care,

The clinician receiving a request to take over the care of a patient being evaluated for transplantation or on the National Transplant List shall consider the request and accede wherever clinically appropriate.

The clinician should inform the patient and family and all relevant health care and other professionals when care will be or has been transferred and ensure all have full contact details.

3.3.2.1 Repeating tests and investigations:

During evaluation and follow-up, patients undergo many tests and investigations to assess their suitability for transplant and for monitoring progress of disease and seeking complications. Some of these tests are invasive (such as biopsy or intra-venous or intra-arterial catheterisation) and these and others (such as radiological examinations) may be associated with potential risk. Accepting clinicians should not repeat such tests without due consideration and justification.

3.3.2.2 Consent/Authorisation

Patients listed for transplantation should have been given all relevant information regarding the benefits, risks and implications of solid organ transplantation and have given informed consent. This should include appropriate consent for risk factors associated with donors. Although this consent will be valid when the patient changes medical team, it is prudent that the team ensures the patient has given fully informed consent and this is recorded in the medical records.

3.3.2.3 Notification

When the patient has been accepted by the new team, then the new team should inform NHSBT in writing of the change. A patient's period of waiting time on the transplant list will remain continuous if the transfer is reported appropriately to NHSBT such that where waiting time is relevant to allocation, the patient will not be disadvantaged.