NHS Blood and Transplant

LIVING DONOR LIVER TRANSPLANTATION (LDLT)

PROJECT BOARD

TERMS OF REFERENCE

1. BACKGROUND

Living donor liver transplantation (LDLT) emerged in 1989 in response to the donor organ shortage created by the discrepancy between donor graft supply and demand, particularly for children requiring size-matched deceased donor grafts. Expanded use of 'split' liver grafts for some children in recent years, has made great inroads into reducing the paediatric waiting list but the use of LDLT in children remains low. A recent North American systematic review of worldwide data showed that despite having a higher paediatric end-stage liver disease (PELD) score at transplant, LDLT recipients (in comparison with deceased donor liver transplant (DDLT)) had improved graft and patient survival and lower rates of acute cellular rejection (ACR) post-transplant. In addition, and contrary to a widely held pre-conception, the risk of post-operative technical complications was similar between DDLT and LDLT in these children. Based on this analysis, a UK strategy to increase the option of LDLT for children is needed to address the critical issues of organ shortage, reduce mortality on the waiting list and optimise long-term survival of paediatric liver transplant recipients.

Due to the scarcity of deceased donor organs in Asia, the utilisation of LDLT in the adult population in the East has grown exponentially over the last 20 years. For various reasons this expansion within the adult end-stage liver disease (ESLD) community has not been reproduced in the UK where LDLT still makes up a small proportion of total liver transplants performed (< 2%) annually. Despite a growing body of evidence demonstrating superior survival outcomes in LDLT in addition to many other advantages including shorter cold ischemia times, improved and timely pre-transplant medical optimisation and expansion of transplant eligibility, the clinical community's concern about donor risk and the technical challenge of the procedure pose significant hurdles to increasing rates of adult-to- adult LDLT. To overcome these hurdles, increased centre experience (to minimise donor risk) and a paradigm shift in attitude and acceptance by the UK liver transplant community to embrace LDLT as a required option for patients to consider - rather than one that is only offered at the discretion of individual clinicians managing their patients, is needed.

The *UK Organ Donation and Transplantation Strategy 2030: Meeting the Need*[1] supports the development of a UK-wide LDLT programme to ensure that suitable patients are given the opportunity to be referred to an experienced, capable centre for consideration of LDLT as one of a range of transplant options that may be appropriate for them. If this can be achieved within a coherent, UK-wide approach, it will help to address the growing waiting list in the aftermath of the SARS CoV 2 pandemic and dramatically increase access to liver transplantation for patients who are eligible to be considered within the new expanded indications that are coming on-line.

2. WHY DO WE NEED A PROJECT FOR LDLT?

To deliver a UK-wide programme that improves access to LDLT as one of a range of transplant options for adults and children with end-stage liver disease.

[1]UK Organ Donation and Transplantation Strategy 2030: Meeting the Need
https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/meeting-the-need-2030/

3. WHAT DOES IT NEED TO ACCOMPLISH?

There are four primary aims of the project, to:

a. Ensure that all suitable patients (adults and children) are offered the opportunity to consider LDLT as an option for them
b. Address barriers leading to unwarranted variation in access to and referral for LDLT (e.g.; geographical, financial, ethnicity/culture, socio-economic circumstances)
c. Ensure that outcomes and experience for both living liver donors and transplant recipients are considered
d. Embed a safe and sustainable LDLT service across the UK alongside the ongoing initiatives to improve organ utilisation including NRP for DCD donation and machine perfusion

4. HOW WILL IT BE APPROACHED AND WHO WILL BE INVOLVED?

A LDLT Project Board will be established to oversee delivery with representation from key stakeholder organisations and individuals, including NHS Blood and Transplant (NHSBT), NHS England (NHSE), Healthcare professionals and lay members. The Project Board will meet quarterly to bi-annually to monitor progress and provide support for workstream leads. Frequency of meetings will be determined by progress of the overall project. The Board will meet virtually or face to face with at least one face to face meeting annually.

The LDLT Project Board will agree workstreams and appoint workstream leads, from a wider stakeholder group to include multi-professional/multi-centre clinical representation, support services (e.g.; radiology), NHSBT representatives, lay and patient members. The constitution of individual workstreams will vary according to the work undertaken and membership will be agreed with workstream leads and approved by the Project Board.

The agreed workstreams are:

1. Operational model and workforce resilience and sustainability
2. Indications for LDLT donor and recipient assessment and follow-up
3. Educational resources – donors, recipients, professionals
4. Commissioning

Together, the outputs from the workstreams will define a safe and sustainable plan for LDLT in adults and children. The plan will require endorsement from key stakeholders – clinicians, patients, NHSBT and commissioners from all 4 UK nations to ensure that funding and accountability for delivering different aspects of the service are clearly defined for each stakeholder group/organisation.

5. HOW WILL SUCCESS BE MEASURED?

The Project will aim to deliver its key aims over 5 years, subject to progress and review. The priority is to present a well-defined, safe and sustainable plan for LDLT in adults and children to commissioners. This will inform the development of future service specifications and ensure appropriate funding through commissioning. The plan will include:

- Clear deliverables for each element
- Establishing a 'Hub and Spoke' model that serves the UK population
- Developing an operational model for LDLT (adult and children)

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https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/meeting-the-need-2030/

- Monitoring the improvement in referrals and transplants (to be set by the board)
- Ensure robust governance is in place

Each workstream will develop an annualised project plan with key milestones and outcomes against which progress will be mapped and reported to Transplant Commissioners (NHSE and Devolved Nations), NHSBT Liver Advisory Group and OTDT Senior Management Team.

6. WHAT RESOURCES WILL BE REQUIRED TO DELIVER THE PROJECT?

A detailed analysis of resources and associated costs required to deliver the project will be drawn up, dependent upon the number of workstreams and their plans. The Project will be led by the Associate Medical Director for Living Donation and Transplantation, supported by members of the NHSBT Clinical Team and in collaboration with colleagues across OTDT. The following resource implications will be taken into consideration:

- Infrastructure required in both referral centres and transplanting centres for
    - Service delivery
    - Workforce training and development
- People to support the delivery both strategically and operationally
- Travel and reimbursement of expenses (professionals)
- Meeting venues
- Digital support (already considered in living donation digital transformation project TS2/TS3)
- Reimbursement of expenses for living donors

7. MEMBERSHIP

Lisa Burnapp (Chair)	**Associate Medical Director – Living Donation and Transplantation, OTDT, NHSBT**
Varuna Aluvihare	Consultant Hepatologist, King's College Hospital
Joshua Bell	Consultant Radiologist, Leeds (working in workstream in assessment
Emma Billingham / Karen Quinn	Head of Commissioning, OTDT, NHSBT / Assistant Director, UK Commissioning and Service Development, OTDT, NHSBT
Derek Manas	Medical Director, OTDT, NHSBT
Sarah Matthews	Lay Member, NHSBT
Katie McGoohan	Advanced Nurse Practitioner, Liver Transplant Services, Leeds
Raj Prasad	Consultant HPB Surgeon, Leeds
Douglas Thorburn	Consultant Hepatologist, Chair of LAG, Royal Free Hospital
Sarah Watson	Specialised Commissioning, NHS England
Julie Whitney	Head of Service Delivery - OTDT HUB, OTDT, NHSBT

In copy:

John Richardson	Assistant Director, Organ Donation, OTDT, NHSBT

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