# Living Liver Donation at the Edge of Uncertainty

A young family donor comes forward for a critically ill infant with an undiagnosed condition



Julie Jeffery
Advanced Clinical Practitioner Liver Services /
Living Liver Donor Team
Leeds Teaching Hospitals NHS Trust

# The case: one urgent decision, two patients

## The infant

Critically ill with liver failure.

Diagnosis remains uncertain; prognosis incompletely defined.

Time may be short, and deceased-donor access may not match the clinical window.

## The proposed donor

A young adult family member volunteers for living liver donation.

They are healthy enough to enter assessment, emotionally invested, and may perceive donation as the only meaningful action available.

## The ethical problem

Can it be justified to expose a healthy person to potential non-trivial harm when the recipient's diagnosis—and therefore expected benefit—remains uncertain?

And what counts as a truly voluntary choice inside a family crisis?

**Central tension: Does urgency increases the value of action ?—but can urgency reduce the quality of deliberation?**

# Clinical Summary

Birth, early course and multisystem findings

NHS

## BIRTH & EARLY COURSE

- Male, born 16 Jan 2024 at 37+5 weeks; birth weight 2.45 kg
- CTG pathology and reduced movements prompted emergency C-section
- Poor condition at birth; ventilated for 10 days
- No infection risk factors

## RESPIRATORY & CARDIOVASCULAR

- Respiratory distress syndrome
- Severe metabolic and lactic acidosis with hypotension
- Patent ductus arteriosus and atrial septal defect

## NEUROLOGY

- Absent Moro reflex and abnormal CFM; cooled for 72 hours
- HIE with seizures; EEG showed epileptic activity
- D1 micro-haemorrhages
- MRI – medullary vein thrombosis
- Reduced vision

## HAEMATOLOGY

- Platelet count 25 × $10^9$/L
- Atypical lymphocytes on blood film
- Deranged clotting treated with vitamin K
- Bone marrow showed reactive changes only

## RENAL & METABOLIC

- Microscopic haematuria; day 3–4 oliguria and acute kidney injury
- Severe hypoglycaemia
- Hypophosphataemia and hypokalaemia

## GI & HEPATIC

- Jaundice and abdominal distension
- Day 3 ultrasound: normal liver morphology; no biliary dilatation
- Ascites, echogenic liver, portal hypertension and splenomegaly
- Biopsy: brisk cholestatic pan-acinar necrosis

# Clinical Summary

NHS

## Diagnosis

**Decompensated liver failure with no identified aetiology**
**Neurological prognosis remains uncertain.**

- Gross ascites requiring repeated drains
- Episodes of sepsis
- Upper GI bleed with cardiovascular instability
- Virology screen negative
- Rapid genome: no pathogenic variant
- Mitochondrial genome: no genetic cause identified

## Transplant timeline

| | |
|---|---|
| **16/01/24** | Born |
| **23/03/24** | Transferred to Leeds |
| **14/05/24** | Listed for Liver Transplantation |
| **30/05/24** | PICU admission for upper GI bleed and cardiovascular instability |
| **04/06/24** | Parents counselled regarding high-risk procedure |
| **04/06/24** | Living donor liver transplant |

# Donor CG

NHS

## Living donor profile

| | |
|---|---|
| **Age / sex** | 21-year-old male |
| **Relationship to recipient** | Cousin |
| **Occupation** | Currently serving in the Royal Navy |
| **Baseline health** | Normally fit and well |
| **Smoking status** | Non-smoker |
| **Alcohol intake** | Minimal alcohol intake |



## Assessment Timeline



# Ethical balance in the decision to proceed

**The donor is not merely a means to rescue the child.**
**The infant is not merely a justification for donor risk. Ethical analysis must hold both lives in view simultaneously**

### Time-sensitive benefit

Living donation created a transplant opportunity within a clinically meaningful window when waiting for DD risks death or irreversible deterioration.

### Respect for donor autonomy

A competent adult may rationally accept personal risk for a deeply valued relationship.

### Potential life-saving benefit

When the alternative is death or irreversible decline, even uncertain recipient benefit may carry substantial ethical weight.

### Two-patient duty

The team owes the healthy donor an independent duty of care; recipient urgency must not lower donor-selection thresholds.

### Family values matter

For some donors, not being allowed to donate can itself produce moral distress, regret or a sense that a core commitment was denied.

### Consent under pressure

Love, guilt, family expectations and fear of a child dying can create powerful internal or external pressure without overt coercion

**Proceeding is defensible only when benefit remains plausible, donor risk is acceptable, and consent is informed and voluntary.**

Sources: WHO Guiding Principle 3 (2010). Rattanavipapong W et al., Transplantation 2024, PMID 38015449.









# Questions designed to make the room uncomfortable—in a useful way

Is refusing a competent donor paternalism—or protection?

How much diagnostic uncertainty is too much when the alternative may be death?

Does emotional load affect clinical judgement
Deeply difficult high stakes decisions
Tight time constraints

Can consent be fully voluntary when the moral alternative feels like ‘letting the baby die’ is there NO choice?

Whose uncertainty should carry more weight: the donor’s risk, or the recipient’s chance of benefit?

If the transplant fails, what would we wish we had discussed before accepting the graft?

Does Rapid time-line of assessment
affect informed consent for donor ?
limit capacity to absorb & process information ?
is it difficult for the donor due to the emotional charge to step away ?

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The aim is not consensus at any cost; it is transparent, defensible reasoning under uncertainty.

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