

Understanding NICE guidance

Information for people who use NHS services

Liver transplants from living-donors

NICE 'interventional procedures guidance' advises the NHS on when and how new surgical procedures or procedures that use electromagnetic radiation (such as X-rays, lasers and gamma rays) can be used.

This leaflet is about when and how liver transplants from living-donors can be used in the NHS in England, Wales, Scotland and Northern Ireland. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence).

This leaflet is written to help people who have been offered this procedure and people who are considering becoming a liver donor to decide whether to agree (consent) to it or not. It does not describe the procedure in detail – a member of your healthcare team should also give you full information and advice about these. The leaflet includes some questions you may want to ask your doctor to help you reach a decision. Some sources of further information and support are on the back page.

Interventional procedures guidance makes recommendations on the safety of a procedure and how well it works. The guidance does not cover whether the NHS should fund a procedure. Decisions about funding are taken by local NHS bodies (primary care trusts and hospital trusts) after considering how well the procedure works and whether it represents value for money for the NHS.



What has NICE said?

Liver transplants from live-donors can be offered routinely as a treatment option provided that doctors are sure that:

- the patient and/or their parents understand(s) what is involved and agree(s) to the treatment, and
- the results of the procedure are monitored.

Donors face significant risks including in some cases death. Doctors should make sure that extra steps are taken to explain the potential risks to both the patient and the donor. This should happen before the donor and patient agree (or don't agree) to the procedure. The patient and donor should be given this leaflet and other written information as part of the discussion. There should also be special arrangements for monitoring what happens after the procedure.

The UK Transplant Liver Advisory Group has developed standards that should be used to ensure the right patients are selected. NICE has also recommended that this procedure is performed in a specialist centre by a team of healthcare professionals.

Patients and donors should be entered into the UK and Ireland Liver Transplant Audit.

This procedure may not be the only possible treatment for end-stage liver disease and primary liver cancers. Your healthcare team should talk to you about whether it is suitable for you and about any other treatment options available.

Living-donor liver transplantation

The procedure is not described in detail here – please talk to your specialist for a full description.

Liver transplantation is an option for patients with end-stage liver disease and some types of primary liver cancer. Organs for transplants can come from dead donors (called cadaveric-organ donors) or living donors. A living donor is usually (but not always) a blood relative (for example, a parent, brother or sister).

The donor has surgery to remove either the right lobe of the liver (usually for an adult) or the left lobe (usually for a child). The right lobe is larger than the left and is easier to transplant. However, removing it from the donor is more complex and presents more risks.

The donated liver is transplanted immediately into the patient.

Summary of possible benefits and risks

Some of the benefits and risks seen in the studies considered by NICE are briefly described below. NICE looked at 10 studies including three reviews on this procedure.

How well does the procedure work?

Many of the studies were carried out in countries where transplants from dead donors are not carried out. The types of patients chosen for the procedure may be different in these countries. This means that the data may not reflect what happens to patients in the UK. A review, looking at how well children were doing 5 years after receiving transplants from living adult donors and dead adult donors, was generally positive. Survival was higher in children receiving liver transplants from living donors at 92% compared with 81% seen in children receiving livers from dead donors. The liver tissue transplanted also survived in more children receiving live-liver transplants: 81% compared with 73%.

For transplants between adults, survival rates were similar for transplants from live and dead donors.

Nearly all donors returned to normal life by 6 months after surgery. By this time, the donor's liver had recovered to 89% of its original size. Few studies have looked at psychological effects of organ donation or the effects on the donors' quality of life.

You might decide to have this procedure, to have a different procedure, or not to have a procedure at all.

What does this mean for me?

NICE has said that this procedure is safe enough and works well enough for use in the NHS. If your doctor thinks that liver transplant from a living-donor is a suitable treatment for you, he or she should make sure you understand the benefits and risks of the procedure before asking you to agree to it.

If you are considering donating your liver, your doctor should make sure you understand the benefits and risks of the procedure before asking you to agree to it.

Patients and donors should be given written information, including this leaflet, and have the opportunity to discuss it before making their decision.

You may want to ask the questions below

- What does the procedure involve?
- What are the benefits?
- How good are the chances of getting those benefits? Could having the procedure make me feel worse?
- Are there alternative procedures?
- What are the risks of the procedure for me?
- Are the risks minor or serious? How likely are they to happen?
- What care will I need after the operation?
- What happens if something goes wrong?
- What may happen if I don't have the procedure?

Expert advisers comments that this procedure has been routinely offered as a treatment for end stage liver disease, particularly for children. They also said that there were uncertainties about the long-term survival of patients, and their liver function.

Risks and possible problems

Common problems related to the connection between the transplanted liver and the gall bladder (occurring in 5–14% of patients in four studies). Thrombosis in the arteries and veins of the liver, and infection also occurred.

In a review of donor outcomes, twelve out of 6000 donors died (0.2%), and the risk seems to be higher with donation of a right lobe (0.23–0.5%) compared with donation of a left lobe (0.05–0.21%).

Over 131 studies, an average of 16% of donors experienced problems affecting the liver, lungs or small bowel, or bleeding. Problems were more common following right-lobe donation compared with left-lobe donation.

The expert advisers expressed concerns about risk to the donor. They noted that some donors may develop liver problems and themselves require a transplant. They also noted that the risk of death depended on the size of the liver lobe donated, and that the risk was higher when the right lobe was donated.

More information about liver transplants from living-donors

NHS Direct online (www.nhsdirect.nhs.uk) may also be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further advice and support.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider how well an interventional procedure works and how safe it is, and ask the opinions of expert advisers. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This leaflet and the full guidance aimed at healthcare professionals are available at www.nice.org.uk/IPG194

You can order printed copies of this leaflet from the NHS Response Line (phone 0870 1555 455 and quote reference N1139).