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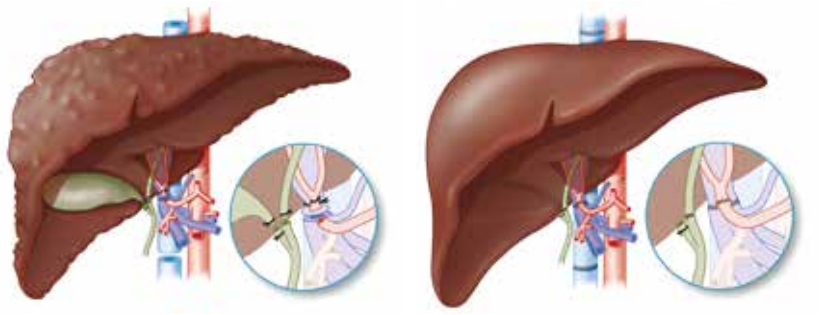


Liver Transplant – Patient information

Patient information

IMPORTANT INFORMATION WHEN YOU ARE CALLED IN FOR A TRANSPLANT

- ✔ Always meticulously follow the instructions issued by the physician or transplant coordinator when you are called in for a transplant.
- ✔ You will be contacted by telephone when a suitable donor organ has been found. This can happen at any time, day or night. Always keep your mobile with you and ensure that the battery is charged.
- ✔ Don't eat or drink anything once you are called in.
- ✔ Bring any medication you are taking with you. This also applies to transdermal patches, creams and homeopathic medicines.
- ✔ Transplantation is not without risk. A number of these risks are described in this document. It is important, therefore, to read it in detail.
- ✔ By placing you on the waiting list for a transplant your physicians have decided that the risk of a fatal outcome as a result of a transplant is lower than the risk of death without a transplant. There may be other potential risks associated with a transplant. Your physician will be happy to provide extensive information on this upon request, before you sign the consent form.
- ✔ If necessary contact your

  hepatologist (tel. 016 34 42 99),
  transplant surgeon (tel. 016 34 87 27)
  or a transplant coordinator (tel. 016 34 29 01)
  should you have further questions.

  For non-urgent questions, please contact transplantatiecoordinatie@uzleuven.be.

WHAT SHOULD YOU BE AWARE OF CONCERNING THIS CONSENT FORM?

You will be asked to give your consent for transplantation as a treatment for your liver disease.

A transplant is a life saving, but difficult and complex surgical intervention. Before you give your consent for transplantation, we would like to provide you with more information concerning the organisation of a transplant and its potential benefits and risks. This will enable you to make a decision on the basis of accurate information. This process is referred to as 'informed consent'.

We would consequently ask that you carefully read the information provided on the next few pages. Should you have further questions you can contact your hepatologist (tel. 016 34 42 99), transplant surgeon (tel. 016 34 87 27) or a transplant coordinator (tel. 016 34 29 01).
For non-urgent questions you can contact transplantatiecoördinatie@uzleuven.be

Your consent is voluntary. You are entitled to review your decision concerning a transplant at any time. If you no longer wish to have a transplant discuss the matter with your hepatologist and notify the transplant coordinator, to ensure that you are removed from the transplant waiting list.

For questions concerning your rights as a patient you can contact the ombudsman at the hospital (tel. 016 34 48 18).

WHY HAVE I BEEN ADVISED TO UNDERGO A LIVER TRANSPLANT?

YOU ARE SUFFERING FROM IRREVERSIBLE LIVER FAILURE

You were advised to have a liver transplant because your own liver is failing or damaged, and will in all probability not recover. This is referred to as 'irreversible liver failure'.

Liver transplantation is associated with a real risk of serious complications. Nevertheless, your medical team has decided that the risks associated with a liver transplant are lower than the risks involved in not having a transplant. They will have discussed this with you.

It is important for you to know that you do not have to undergo a liver transplant if you don't want to. However, liver transplantation is the only form of treatment for irreversible liver failure and could save your life.

If you do not want to proceed with a liver transplant, we can only treat the symptoms/side effects of liver failure such as jaundice, fluid retention, loss of consciousness and gastrointestinal bleeding.

YOU ARE SUFFERING FROM LIVER CANCER AND HAVE BEEN OFFERED A TRANSPLANT

With certain liver cancers (hepatocellular carcinoma) a liver transplant can offer a better prognosis than other treatments, be it surgical, interventional or medicinal. These types of liver cancer must meet strict conditions in order to qualify for transplantation.

Again it is important for you to know that you do not have to undergo a liver transplant if you don't want to. Liver cancer can be treated using other means but probably not cured. Your hepatologist can discuss these other options in detail with you and explain the potential advantages, disadvantages and expected results.

If you opt to undergo a liver transplant and are waiting for a suitable donor, the further progress of your liver cancer will be closely monitored by your hepatologist. Sometimes the cancer's progress during the waiting time can make it clear that a treatment other than transplantation may be more appropriate at that time.

YOU ARE SUFFERING FROM A LIVER DISORDER THAT IS HAVING A SIGNIFICANT IMPACT ON YOUR QUALITY OF LIFE

You were advised to have a liver transplant because you are suffering from a liver disorder such as polycystic or cholestatic liver disease, etc. This disease is causing symptoms that are difficult to treat. The medical team in charge of your treatment has come to the conclusion that you are suffering from serious and objectifiable complaints that are having a serious impact on your quality of life.

Your liver is still functioning satisfactorily with this disease and there's no risk of irreversible liver failure, which means that a liver transplant would not be a life saving intervention. It is important, therefore, that you are aware that you do not have to undergo a liver transplant if you don't want to.

The objective of a liver transplant is to improve your quality of life. However, the operation is associated with a real risk of serious com-

plications, including death. That is why the risks associated with a liver transplant need to be carefully weighed against the results of further medical treatment. This will be discussed with you.

If you don't want to undergo a liver transplant, the alternative will depend on the exact nature of your disease. You can discuss this in detail with your hepatologist.

HOW LONG WILL I HAVE TO WAIT FOR MY TRANSPLANT?

The waiting time for a liver transplant greatly depends upon the seriousness of your liver disorder and the suitability and availability of a donor liver. The average waiting time for a liver transplant within Eurotransplant (the organ allocation body of which Belgium is a member) varies. Approximately 70 in 100 patients receive a transplant within a year of being placed on the waiting list. The remaining 30 in 100 patients have to wait (much) longer for a suitable offer.

Some patients die before they can be given a transplant. The risk of dying before a liver transplant is approximately 15 in 100 (15%) and depends upon, for example, the cause and seriousness of the liver disorder.

Sometimes a patient's condition will deteriorate to the extent that transplantation is no longer possible, in which case they will be removed from the waiting list. Should this happen it will always be discussed with you.

WHAT HAPPENS AFTER I AM CALLED IN FOR A TRANSPLANT?

You will be called in by the hepatologist on call, which can happen at any time of the day or night. The reception desk at the main entrance to the hospital will get someone to accompany you to nursing unit E 446 (green arrow, 4th floor), the same unit where you were hospitalised for a pre-transplant assessment.

Upon arrival at E 446 you will be welcomed by the nursing team. A physician will check your medical records and run through your medical history with you. They will also examine you and ask a few questions concerning your current state of health. Blood samples will be taken for additional standard analyses. You will also be given a chest X-ray (lungs) and ECG, and a few other tests may be carried out.

You will then be prepared for transplantation. The donor liver will have been removed from someone who has recently died. Occasionally part of the liver of a healthy person may be donated. Once the donor liver has been approved by the donor surgeon and the operating theatre and surgical team are ready to carry out the transplant, you will be taken to the operating theatre. Sometimes there is little time between your arrival at the hospital and the transplant. Having said that, it can take several hours before you are actually operated on.

The examinations and tests and/or examination of the donor liver can in some cases reveal that a liver transplant is not possible. For example, if the liver is of poor quality or because an unexpected problem is identified during your examinations (e.g. an infection). A

transplant is only cancelled if the physicians are of the opinion that the transplantation of that specific liver would not benefit you. In such cases do not hesitate to ask the transplant team for further explanation to ensure that you understand why the decision was taken. You will still remain active on the waiting list though.

In exceptional cases unexpected problems may occur during a transplant that would make it unsafe to continue the transplantation process. Typical examples of such problems include technical difficulties during the operation or an unexpected discovery relating to you or the donor liver. In such cases the operation will be interrupted and you will be informed by your medical team as soon as you regain consciousness.

WHO WILL CARRY OUT MY LIVER TRANSPLANT?

Your liver transplant will be carried out by an experienced, highly trained surgical team led by a member of staff of the abdominal transplant surgery department on call at that time.

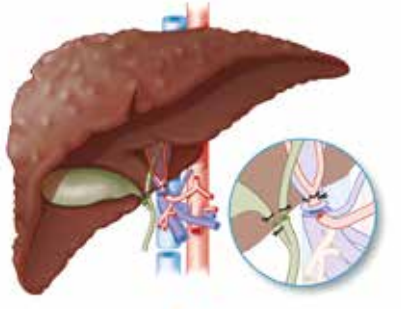
WHAT WILL HAPPEN DURING THE OPERATION?

A liver transplant is conducted under a general anaesthetic. You will have the opportunity to discuss the potential side effects and risks associated with a general anaesthetic in detail beforehand with an anaesthetist during the pre-transplant assessment. During a general anaesthetic several small tubes (infusion lines) are inserted intravenously in the arm and neck to administer fluids and medication, take blood samples and to monitor you during and after the transplant. We also insert a gastric tube via the nose and a bladder catheter during the operation to drain urine and monitor your urine production. Your breathing will be managed via a tube inserted in the trachea (windpipe) during the operation.

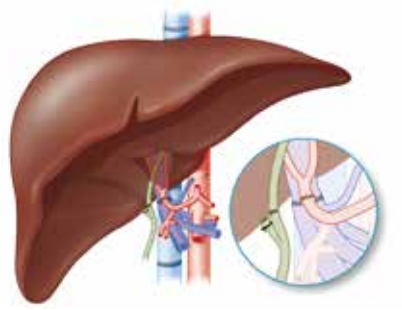
The surgical team will prepare the donor liver for transplantation and transplant it into your body. The surgeon will make a long horizontal incision in your upper abdomen, just below the ribcage arch. Your diseased liver will then be removed and replaced by the donor liver, by connecting the blood vessels and bile duct. Because blood from the legs and intestine passes through the liver, it usually has to be temporarily diverted during the transplant, which is done via several tubes inserted in blood vessels in the leg and arm. This will require additional incisions in the groin and armpit. A few drains will be left in the wound following the transplant to allow blood and fluids to drain away from around the liver. These tubes are usually removed after a few days.

A liver transplant takes approximately 5 to 8 hours, but can sometimes take longer.

It is often necessary to administer blood or blood products during or after a transplant.



Removing the diseased liver



Replacing it with a donor liver

WHAT WILL HAPPEN AFTER THE OPERATION?

You will sleep and continue to be connected to a ventilator after the operation. You will be transferred to the intensive care unit, where you will be looked after by a specialist nursing team led by a consultant specialist. As soon as your condition allows you will be woken up and the ventilation tube removed from your trachea. Most patients are woken up the day after the transplant, although it may take longer. In most cases patients can leave the intensive care unit after a few days. You will then be admitted to E 662, the abdominal organs transplantation unit. However, it may be necessary to keep you in the intensive care unit for longer. Further information concerning your stay in the intensive care unit can be found in the 'Intensive care' information brochure.

Food and drink: normally you will be allowed to eat and drink again within a few days of regaining consciousness, once your intestine is again functioning properly. Sometimes this may take longer, but in the meantime you will receive all the necessary nutrients via a drip.

Movement: in order to prevent blood clots we will encourage you to move around and get out of bed as soon as possible.

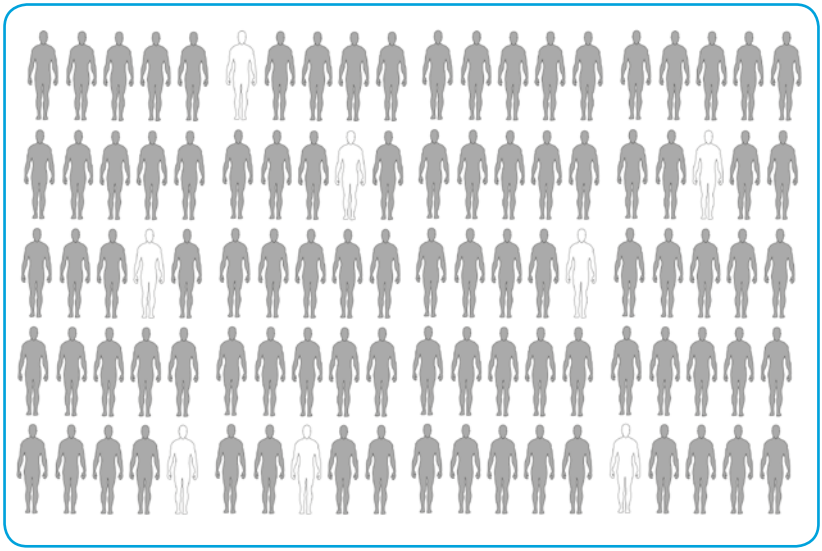
Going home: you will have to stay in hospital for between 10 and 20 days following a liver transplant. However, the duration of your stay will depend on your general progress and the functioning of the donor liver. In some cases patients have to stay longer in hospital. Once you are at home you will be able to undertake light daily activities, but it can take several months before you are able to return completely to normal activities.

Check-up consultations and medication: you will have to be meticulous about taking your medication and also attend regular check-ups. Further information is provided in the brochure entitled 'Living with a new liver'.

WHICH SIGNIFICANT, UNAVOIDABLE OR FREQUENT RISKS ARE ASSOCIATED WITH A TRANSPLANT?

DEATH

A liver transplant is a difficult and complex operation with a success rate of approximately 92 in 100 (92%). This means that 8 in 100 liver transplant recipients will die in the first year following the transplant. A very small number of these patients (1 in 100) will die during the transplant. The illustration below will help you make sense of these figures. The chance of you dying during the first year following a liver transplant is about the same as the chance of you picking an ace from a deck of cards.



The grey figures in the above illustration represent the patients who are still alive one year after a liver transplant. The white figures represent the patients who will die during the first year following a liver transplant.

TRANSPLANT LIVER DOESN'T FUNCTION

There is a small chance of the transplant liver not functioning following the operation (2 in 100). If that were to happen to you, you would need an emergency (within a few days) replacement transplant liver (another transplant) in order to survive. In such cases you are given absolute priority on the liver transplant waiting list, to ensure that the next available liver within Eurotransplant is offered to you. There is a 2 in 3 chance that a new donor liver is found in time.

THROMBOSIS

There is a small risk (4 in 100) of a clot developing in a blood vessel in the transplant liver. If that happens within the first two weeks of the transplant, you will need an emergency re-transplant. Again you will be given priority on the liver transplant waiting list; similar to what happens with a transplant liver that isn't functioning.

FURTHER OPERATIONS

There is a chance (10 in 100) of you requiring further operation(s) shortly after the transplant to stop bleeding or remove blood clots. In general there is a 15 in 100 chance that you would need an additional operation to manage complications during the first month following the transplant.

BILE DUCT PROBLEMS

During the transplant the bile duct of the donor liver is connected to your bile duct (or sometimes a section of the intestine) to allow bile to flow into the intestine. This connection may leak resulting in bile seeping into the abdomen. The bile has to be drained away and this may require a second operation.

Scar tissue may also form and become a problem at the connection, preventing the bile from draining properly. In such cases the narrowed opening has to be stretched. To do so the hepatologist will use a balloon, which is inserted and inflated in the narrowed section. A stent is often left behind in the bile duct to prevent it narrowing again during the healing process. The intervention (ERCP) is conducted via a camera under a light anaesthetic and using tiny instruments that can be inserted up to the bile duct via the stomach. This procedure may have to be repeated several times.

Another problem associated with bile ducts is the narrowing of the small bile ducts in the liver. In such cases it is extremely rare that a definitive solution involving balloons and stents can be offered. If the functioning of the liver is jeopardised due to extensive narrowing of, and damage to, these small bile ducts in the liver, a new transplant will be proposed.

OTHER COMPLICATIONS

As with any other operation, there is a risk of complications such as wound infections, blood clots in the legs or lungs, fluid leakage from the drains or wound. These complications can often be treated with medication or additional wound care. There is also a risk of a

heart attack following the operation. To minimise the risk of this happening you will have undergone several tests to establish whether your heart is strong enough to withstand the operation.

Rejection: The risk of acute rejection of the liver is approximately 25 in 100 (25%). If there are significant signs of rejection you will be given stronger anti-rejection medication. In most cases they will control the rejection, but you will have to be admitted to hospital.

RE-OCCURRENCE OF LIVER DISEASE

Some liver disorders can recur in the transplant liver and be a cause of transplant liver failure. These are mainly disorders associated with the immune system (e.g. primary biliary cirrhosis, primary sclerosing cholangitis and autoimmune hepatitis) and diseases resulting from viral infections such as hepatitis C and hepatitis B.
Hepatic steatosis can also return in a transplant liver. Liver cancers (such as hepatoma, hepatocellular carcinoma or cholangiocarcinoma) that are present in a liver with cirrhosis at the time of the transplant may also recur in a number of patients.

Other complications that are not described here may also occur.

WHICH RISKS ARE ASSOCIATED WITH THE DONOR LIVER?

This paragraph focuses on the donor liver and some of the risks associated with the transplantation of a donor liver. There may be other risks associated with a donor liver that are not described here.

Even though your donor liver is new to you, it is not actually a new liver. Organs are donated by someone who has recently died, who wanted to help someone in your situation following their death. Most organ donors have died as a result of a medical condition such as a stroke or heat attack. The average age of organ donors in Eurotransplant – and in Belgium – is rising. In 2015 the average age was 54 with some donors being older than 80. In 2014 (1 in 4) 25% of liver donors were older than 65.

DISORDERS THAT CAN BE TRANSMITTED BY THE DONOR

Some donors may have medical problems, which we are not aware of when they die, but that can be transmitted to you. We make every effort to check for the presence of life threatening infections in organ donors, but some donors may suffer from a viral infection that we are either not aware of or consider to be low risk in your case. A typical example is the cytomegalovirus, which we can treat after a transplant. An infection with hepatitis B is also treatable because we can administer medication which prevents the activation of the hepatitis B virus in the recipient following the transplant. The risk of you being infected with a life threatening infection originating from your donor is very small (less than 1 in 100).

Some donors have an increased risk of a hepatitis virus or HIV/Aids because they used intravenous drugs or because of their life style. All organ donors are meticulously checked for the presence of viruses. There is, however, a small chance (approximately 1 to 2 in 100) of an infection being missed in a high risk donor and consequently being transmitted to the recipient. If such an infection is transmitted to you, you will have to take antiviral medication for life.

Approximately 1 in 2000 organ donors suffers from a type of cancer, which we are not aware of and can be transmitted via the organ. That is often a fatal complication. Unfortunately there is no way in which we can predict which donor has a hidden cancer or when this might occur.

Approximately 2 in 100 donors have died as a result of brain cancer. This type of cancer very rarely spreads to other parts of the body, which is why transplant teams commonly transplant organs from this type of donors. If your organ donor suffered from this type of cancer there is a small chance (approximately 2 in 100) of the cancer being transmitted to you. The chance of the cancer not being transmitted is 98 in 100.

Some donors may have been treated for cancer in the past and were considered cured. We make every effort to obtain detailed information about the cancer and its treatment before we decide whether the organs are safe to be transplanted.

DONATION FOLLOWING BRAIN DEATH OR CIRCULATORY ARREST

An organ donor's death can be established in two ways:

- ✗ brain death: in the event of brain death the brain functions – including brainstem functions – have irreversibly failed. Brain death can be established with certainty using specific examinations. A brain dead donor can no longer breathe independently and is connected to a ventilator, but the heart is still beating and supplying the organs with blood and oxygen.

- ✗ circulatory arrest: some donors have incurred irreversible brain damage but are not brain dead. However, the damage to the brain is so serious that recovery is no longer possible. That is why the attending medical team has decided, in conjunction with the donor's next of kin, to cease providing vital support therapy. As a result the heart will stop pumping (irreversible circulatory arrest) when the heart function has stopped.

Approximately one third (30% in 2015) of the liver transplants that are carried out in Belgium involve a liver originating from a donor who has died as a result of circulatory arrest. This percentage is gradually increasing. Livers originating from donation following circulatory arrest are associated with a slightly higher risk of not functioning following transplantation (3 in 100 instead of 1 in 100) and a higher risk of damage to the bile ducts in the liver (15 in 100 instead of 7 in 100), which may require additional treatment. Sometimes this additional treatment will involve another transplant.

We will only transplant a donor liver, which we expect to be suitable to provide long term liver function and the risks of which we consider acceptable, taking into account your condition and your risk of dying whilst on the waiting list.

WHAT SHOULD YOU BE AWARE OF CONCERNING ALCOHOL CONSUMPTION?

If the need for a liver transplant is the result of excessive alcohol consumption in the past, you will have to have stopped drinking any alcohol for at least 6 months in order to qualify for a liver transplant. Anyone agreeing to a liver transplant must commit to consistently and permanently refraining from the consumption of alcohol, both before and after the liver transplant. You will have to consent to this in writing. In doing so you will also consent to regular (unplanned) alcohol level checks being carried out. Analyses showing that you are still consuming alcohol will not be without consequences, such as additional treatments or removal from the waiting list.

The transplant psychologist, transplant psychiatrist and social worker will talk to you about your motivation to undergo a transplant. They will also discuss the rules/routine you will have to adopt after the operation and assess whether or not you are capable of observing them. The multi-disciplinary team may recommend psychological support during the waiting time and/or the period after the transplant. You, or your family, can also make an appointment with the psychologist at any time (during your stay in hospital or during an outpatient consultation).

WHAT SHOULD YOU BE AWARE OF CONCERNING SMOKING?

If you agree to a liver transplant you commit to consistently and permanently refraining from smoking before and after the transplant. Obviously you will have to sign for this as well. Smoking increases the risk of infection, particularly post operative lung infections as well as other infections. The anti-rejection medication used after the transplant increases the risk of developing certain cancers. This risk is much higher in transplant patients who still smoke or start smoking again. Transplant patients who smoke are exposed to a much higher risk of throat, lung and other cancers.

Do not hesitate to ask for support when you stop smoking. Various stop smoking courses are available either at the Gasthuisberg campus or in your area (regional hospitals or health insurance funds). The social worker and psychologist can provide further information.

WHAT IS THE COST OF A LIVER TRANSPLANT?

If you subscribe to the health insurance fund in Belgium most of the cost of a liver transplant is refunded in accordance with RIZIV rules. Our social worker will discuss this and look for solutions with you if you have limited financial means.

Design and implementation
This text was written by the department of abdominal transplantation and transplant coordination in cooperation with the department of hepatology and the communications department.

You can also find this brochure at www.uzleuven.be/en/brochure/700983.

Comments or suggestions pertaining to this brochure can be submitted via communicatie@uzleuven.be.

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