LIVING DONOR LIVER TRANSPLANTATION

A Handbook for Donors and Potential Donors

INTRODUCTION

For many years, the organs required for transplants have been obtained from donors whose families have given their authority after the brain-death of the donor. But since the number of donors was limited, the number of people awaiting transplants continuously grew. This was the reason that many people on the liver transplant waiting list lost their lives without being able to receive a transplant. On the other hand, some of those patients, whose close relatives have donated part of their livers, have been given the opportunity for transplants without having to enter the waiting lists.

Today, living donor liver transplants have become the most important alternative treatment method for many patients with liver failure or tumors who need a transplant.

This booklet answers the questions that donors most frequently ask about the operation, and the period before and after the operation. You should not hesitate to ask your doctor if there is anything you feel you have not fully understood or require more information about. At the Group Florence Nightingale **Center for International Patients**, we are ready and available to assist you in whatever way we can, from helping to keep you fully informed about every aspect of the transplantation procedure to scheduling appointments and coordinating all aspects of your treatment as an international patient.

WHAT IS LIVING DONOR LIVER TRANSPLANTATION?

In living donor liver transplantation, a part of the donor's healthy liver is transplanted to the recipient immediately following surgical removal of the recipient's unhealthy liver.

The liver is different from the body's other organs as it has the capacity to grow and regenerate itself. This allows the possibility of transplantation from living donors. The liver immediately begins to renew itself and continues to do so for a period of about one year. Therefore, the part of the liver that has been surgically removed from the donor and transplanted into the recipient, as well as the part that remains in the donor, both soon return to their original size.

At first, living donor liver transplantation was only carried out through the transplantation of a small part of the donor's healthy liver to children suffering from liver failure. Starting in 1994, adult transplantation began through the removal of a large part of a healthy liver. During this entire period, the Group Florence Nightingale Organ Transplant Center has been at the forefront of global developments in this field.

Q. What are the benefits and advantages of living donor liver transplantation?

A. The fundamental advantage of living donor liver transplantation is that the recipient is able to obtain the transplant without having to wait for an organ from a deceased donor. Patients on waiting lists sometimes have to wait for so long that their condition worsens; patients may die before being able to receive a transplant. Moreover, the patient's general health condition may deteriorate while he or she is waiting, increasing the possibilities of post-operation complications and reducing the chances of success after the transplant has been carried out. We would not have recourse to living donor transplants if there were an adequate availability of organs from deceased donors.

Q. How much of the donor's liver is removed?

A. Generally, 40-70% of the liver is removed. The liver is divided into two - a left lobe and a right lobe. The anatomical division of the liver in this way allows us to obtain two separate and independently functioning liver segments. The right lobe on average comprises 60% of the liver, the left lobe 40%. The donor's gallbladder is also removed during the transplant operation.

Q. How much time should pass between the removal of the liver from the donor and transplantation to the recipient?

A. The two operations are carried out concurrently.

Q. Can anyone be a living donor?

A. Generally, the donor must be between 18 and 60 years of age. It is preferred that the organs of both recipient and donor are of approximately the same size, but in some circumstances the recipient's liver may be smaller than the donor's. Pregnant women cannot be donors. Overweight people cannot be donors, but they may become suitable donors upon losing sufficient weight. The donor should not be suffering from any illness or disease. The donor must be aware of all the risks of this operation, and must follow all short-term and long-term medical instructions after the operation.

Q. Does the donor have to be related to the recipient?

A. In Turkey, a liver donor should have at least a 4th degree relationship to the recipient. Our hospital's board of ethics evaluates cases in which there is no such kinship between donor and recipient.

Q. Is the risk of rejection reduced if I am related to the recipient?

A. Studies have shown that a blood relationship between donor and recipient does not reduce the risk of rejection. Moreover, the degree of post-operation immunosuppressive treatment needed by the recipient is not affected by any blood relationship between donor and recipient. The only

case in which there is any connection of this kind is when donor and recipient are identical twins.

Q. What factors are assessed during the evaluation process?

A. The blood groups of donor and recipient must conform. The evaluation assesses that the donor's liver is normal and of sufficient size. The evaluation also looks at whether the donor has any psychiatric condition that might make it challenging for them to cope with the operation. There must be no possibility of any infectious disease being transferred to the recipient from the donor. Finally, the donor must be under no pressure and must be willing to donate his or her liver entirely as a matter of free will.

Q. Can my own doctor conduct the evaluation?

A. Since the evaluation process is a detailed one, it is preferred that all tests and assessments are conducted by our own team. If you are an international patient living abroad or far from our center, part of the evaluation process may be carried out where you live, but in any event you must be examined by our doctors.

Q. What is the first step of the evaluation process?

A. The first step is to establish your blood group. This is a very simple test that may be carried out by your own doctor or any blood center. The blood group of donor and recipient 1- must either be identical, 2- if recipient "AB" the donor can be in any of groups, 3- if the donor is "0" recipient can be in any of group. It does not matter whether the donor's Rh factor is positive or negative.

Q. If I know my blood group what should I do next?

A. You should contact the Group Florence Nightingale Center for International Patients (CIP) who will coordinate and arrange all necessary procedures and consultations. They will help to answer any questions you have, by phone or e-mail. The CIP staff will take your detailed personal information and help to make necessary appointments. Your medical history and current condition will then be thoroughly reviewed. The doctor assigned to you will give you detailed information about living donor liver transplantation, its risks and statistical data from our Center and internationally. A comprehensive blood test will be carried out and, assuming a positive review of results, the 2nd step will be planned.

Q. What is the 2nd step of the evaluation?

A. The next step is to carry out detailed ultrasonic and computer tomography (CT) examination of your abdomen and liver. Your liver's size, viability and blood supply is measured. The CT scan gives us detailed data about your liver and plays a significant role in the decision-making process. Additionally to this, you will be assessed by a hepatologist and a surgeon from our team. The significance of other tests that may be carried out varies according to your condition.

Q. Should I refrain from eating before medical appointments?

A. You should not eat for a period of 3-4 hours before the CT scan, or a period of 8 hours before a MRCP (a special type of magnetic resonance imaging (MRI) exam that produces detailed images of the liver and gallbladder). Apart from that, unless it is specifically stated by your doctor, you do not need to refrain from eating before appointments.

Q. Should my family accompany me to appointments?

A. It is important for you to have an accompanying family member or close friend with you when you come for appointments, so that they may also be kept fully informed about the procedure and ask any questions or raise any issues they may have in their minds. It is recommended that the person who will accompany you for the operation is with you throughout this process.

Q. When will I find out whether I can be a donor?

A. You are generally informed as soon as the evaluation has been carried out. Sometimes, further tests may be requested. It is essential that you fully understand all information that is given to you. Deciding to donate part of your liver is a serious one.

Q. Who makes the final decision on whether I can be a donor?

A. After all the tests have been carried out, our team meets to assess and review the results. This team consists of doctors, surgeons, coordinating nurses, radiologists, anesthetists, psychiatrists and any consultant doctors who may have examined you. The decision that emerges from this process is never an individual or personal one; it is always made by a team. The decision is always based upon the health and wellbeing of the donor.

Q. If my suitability as a donor has been confirmed, who decides on the date of the transplantation?

A. The surgical team makes a joint decision on the date of the transplantation, in conjunction with the donor and recipient. Our doctors prefer to carry out the transplantation as soon as possible, depending on the nature and seriousness of the recipient's condition. Accordingly, preparation for the operation begins, in consultation with the donor. Operating theater coordination is also important. Two operating theaters are required for the transplantation with 2 teams, each team consisting of a surgeon, nurse and anesthetist.

Q. Should my decision be influenced by the condition of the recipient and the cause of his or her disease?

A. The donor makes a significant sacrifice in deciding voluntarily to donate part of his or her liver. This sacrifice may be life-saving for the recipient. Some conditions (like hepatitis C and liver cancer) may recur after the transplant operation. The expectations and prognosis of the transplantation, possible complications, and the current medical condition of the patient, will be

fully explained to you before the operation. These discussions are kept confidential and the donor is expected to show the same sensitivity in observing confidentiality. The fact that these matters are discussed with the donor is not concealed from the recipient.

Q. What are the possible complications for the donor?

A. There may be a risk of post-operation bleeding and bile leakage. In rare cases this can require blood transfusion and further surgery. While the probability of such a complication is very low, the risk always exists. These risks will be explained to you in detail during the evaluation process. The most commonly experienced complications are small-scale bile leakage, minor infection at the surgical incision site, and certain gastrointestinal difficulties such as constipation, indigestion and nausea. Such complications resolve themselves within a few weeks.

Q. Is the gallbladder removed during surgery?

A. Yes, the gallbladder is removed during the transplantation. The donor does not experience any negative effects as a result of this removal during his or her lifetime after the operation.

Q. Does the donor receive a blood transfusion during the surgery?

A. There is a very occasional need for the donor to receive a blood transfusion.

Q. If I drink, will I need to give up alcohol?

A. If you are going to be a donor, it is advised that you stop drinking. You must inform our doctor if you have a history of heavy alcohol consumption. While having a history of drinking does not in any way disqualify you from becoming a donor, it may nonetheless render it advisable to carry out a precautionary biopsy to check for any possible liver damage.

Q. Do I have to stop taking any medication during the evaluation or in the pre-operation period?

A. Do not stop taking any medication unless our doctors advise you to do so. You should not take aspirin or similar medication for a period of 7 days before the biopsy or operation. As they restrict blood clotting, such medications significantly increase the risk of bleeding-related complications. Women using birth control or hormone replacement therapy are also advised to stop their medication as it hastens blood clotting and increases the risk of complications.

Q. How long should I take off work?

A. The minimum post-operation recuperation period is 4-6 weeks. The exact speed of recovery varies from person to person, and in some cases it can take 8-12 weeks for total recovery from all discomfort and weariness.

Q. How big is the surgical incision wound?

A. The incision wound is long, made in a "J" shape sometimes called a "Mercedes" incision.

Q. Will the incision wound leave a scar after I have recovered?

A. The incision wound generally heals quickly and diminishes over time. But it will always be visible. In the event that any infection occurs, the scar will be larger and more visible.

Q. Will I feel much pain in the period after the operation?

A. Pain control is conducted using an intravenous catheter for the first 3 days following the operation. After that, pain relief tablets are given to limit your discomfort.

Q. Will I be able to lead a normal life after the operation?

A. In the absence of any complications we expect you to return to your normal pre-operation life within 3 months. The risk of long-term complications is very low.

Q. What about my sex life?

A. In all probability you will not feel like having sex for a few weeks after the operation, until your energy and stamina return to normal. The most important factor is how you feel in terms of drive and energy.

Q. If I am considering having a child, how long should I wait after the operation before becoming pregnant?

A. There is no definitive answer to this question, but we advise that you do not become pregnant for a period of 6 months after the operation.

Q. When can I resume my birth control or hormone replacement therapy?

A. We recommend that you wait for at least 3 months after the operation.

Q. When will my liver regain its original size?

A. The liver begins to regenerate immediately. The most intense period of regeneration occurs in the first 2 weeks. Within 3 months the liver will have reached its original dimensions, or close to its original size.

Q. Can I become a liver donor again in the future?

A. No. Having donated part of your liver once, it is not possible to repeat the surgery.

Q. How soon can I start driving again?

A. It is recommended that you do not drive for 4 weeks after the operation. Before you start driving again, you should be in good physical and mental shape, your reflexes should be back to normal, and most importantly you must not have any abdominal discomfort.

Q. When can I start exercising?

A. You will start "exercise" as soon as the anesthetic wears off. You will be asked to perform breathing and coughing exercises and exercises to use the muscles in your legs. You will be able to walk with assistance 24-48 hours after the operation. Walking is an important factor in your recovery process. Getting back on your feet as quickly as possible after surgery will limit the risk of complications such as blood clotting, pneumonia and muscle loss. A walking program that you can follow at home will be prepared for you. Don't forget that the objective is to get you back to your former state in 2-3 months.

Q. When can I do heavier forms of exercise like running, swimming and weight-lifting?

A. You should take care not to lift any heavy objects in the first 6 weeks after the operation, until your abdominal wall has recovered. Do not lift more than 5 kg. If you feel up to it after 6-8 weeks, and as long as you have not suffered any complications, you may return to your normal daily activities, including sports such as running, swimming, aerobics and cycling. You should take particular care to follow abdominal exercises, starting off gradually with slow regular exercises as you build up your strength, stamina and endurance.

Q. When can I start traveling again, and when is it safe for me to fly?

A. You should not make any plans for foreign travel for at least 4 weeks, and preferably for 8-12 weeks. As an international patient living abroad or far from Istanbul, it is normally safe for you to return home within 2-4 weeks as long as your place of residence is close to a doctor with knowledge of living donor liver transplantation, and a medical center where you can have checkups. Our Center for International Patients will handle all necessary with your doctor in your home country. You should bear in mind that if there is the slightest indication of complications, or any need for further surgery or treatment, you may be asked to return to our center. At the end of the 12th week you may travel wherever and however you wish.

Q. Will the transplantation definitely take place once it is scheduled?

A. Unfortunately, when it comes to liver transplantation, there are a number of variable factors that can alter our plans. The recipient's condition may deteriorate to the extent that the transplantation is no longer feasible. Or the recipient may suffer an infection or other condition that requires treatment before the operation can be conducted.

Q. How long will I have to stay in hospital?

- A. The average hospital stay for a donor is 7-10 days.
- Q. Will I be sharing a room with the recipient?
- A. No. The recipient remains in the intensive care unit for 1-2 days before being admitted to a room.
- Q. Does the donor stay in the intensive care unit after the operation?

A. The donor stays in the surgical intensive care unit for one night after the operation, where he or she is kept under close observation. As long as there are no complications or bleeding, the donor is admitted to a hospital room the next day after the anesthesia has entirely worn off and everything has stabilized.

Q. After the operation, when can I eat and drink?

A. You may start eating and drinking after the operation as soon as your bowels start functioning again and you have the first sign of flatulence. You may then safely sip water, and as long as this does not cause you to feel nauseous or to vomit, you may then consume liquids and soft food. You can return to eating normally within a couple of days. Donors do not always return to their normal eating habits so quickly; it should also be remembered that the less pain relief medication you take, the quicker your bowels will return to normal.

Q. Is anything like a drainage tube or the like attached to the donor during the operation?

A. One or two intravenous tubes or drips may be used for the purpose of administering medication or liquid. One will be used to provide you with intravenous pain relief. In addition, a catheter will be placed in your bladder in order to facilitate the monitoring of your kidney function. A small drainage tube will be placed in your abdomen. The intravenous drips and urine catheter are removed after 3-4 days. The drainage tube in your abdomen is removed within 6-7 days.

Q. Will I have to come back to hospital for check-ups?

A. As this is a major operation, we will keep you under observation until it is clear that everything is progressing without any problems or difficulties. You should have a check-up 1 week after being discharged, and a second check-up one month after the operation. You should then have check-ups after 3 months and 1 year.

Q. Should I stay somewhere close to the hospital after the operation?

A. You should stay close to our center for a period of 2-3 weeks after the operation. You should be in a position to return to the center in case any problem arises. It is recommended that you have someone stay with you during this period.

Q. Does the donor need any treatment after donating his or her liver?

A. You will not need any treatment apart from pain relief medication. You will need to take antibiotics in the event that any infection to the incision wound occurs.

Q. After being released from the hospital, will I need any nursing at home?

A. Although this is a major operation and you will feel weak and tired, you will not require any professional nursing assistance. The care of a relative or close friend will be sufficient. You will also need someone to take you to and from the hospital for check-ups.

Q. Do I need to make any special preparations for this operation?

A. All necessary preparations for this operation are carried out entirely at our center. Few additional tests are made after the decision to be a donor has been made. If there are more than 30 days left before the operation, we may ask to repeat some of your blood tests. 2-3 days before the operation, the donor, the recipient and his or her family are asked to come to our center. All details are reviewed and any queries or issues that the patient or his or her family or close ones may have, are answered and fully explained.

Q. Will I be staying at the hospital on the night before the operation?

A. Yes. The donor and recipient are admitted to the hospital on the afternoon or in the early evening on the day before the operation.