

## What is important during the waiting period?

During the waiting period it is especially important that you try to stay in as good physical shape as your illness allows. All the physical strength you can maintain prior to the transplantation will help you during the operation.

Pay special attention to getting enough exercise, such as try to avoid using your car, elevators, etc. When possible, practice a sport. Push yourself, but don't overdo it as that would not be helpful.

Inform yourself about a balanced, healthy diet and plan your meals accordingly. Your doctor can also advise you. They can also inform you about particular diets that may be necessary for certain illnesses or certain complicated types of liver cirrhosis.

If you want to take a longer trip, talk to your transplantation center well ahead of time. Check on the possibility of a fast return trip and make sure you are always reachable by phone. Public health insurers will only pay for domestic transport costs to a transplantation center. If in doubt, it would be better to cancel the trip.

## What about my anxiety?

During the waiting time, in addition to your health problems, comes the added burden of not knowing when a donor organ will be available and how well one will get through the operation. Many of our transplanted members have personally experienced how much this contact with other transplanted patients can really help at this time. One can talk about the experience and see how they are doing following their liver transplantation.

We invite you to do just that. To find a contact person in your area, first call:

**Jutta Riemer**                      Tel. 0 79 46/94 01 87  
**Dieter Bernhardt**              Tel. 0 21 29/37 74 66  
**Peter Mohr**                      Tel. 0 41 31/5 32 17

You may also locate them on our website:

**[www.Lebertransplantation.de/kontakt.htm](http://www.Lebertransplantation.de/kontakt.htm)**

Information about organ donations can also be obtained from the toll-free Tel. 0800/90 40 400.

Sometimes the anxiety can be so burdensome and overwhelming that just talking to those close to you or even with other patients doesn't help. Then an experienced therapist or psychologist may be able to assist you. Your doctor or the clinic should be able to put you in touch with them.

## What comes "afterwards"?

A liver transplantation does not end with the operation. You as the patient now have to assume a lot of the responsibility to recover your health. A successful transplantation, however, does make it possible for you to reclaim your normal life, go back to work and live with a good "quality of life". That makes all your efforts worthwhile.

**Additional brochures are available about:  
Liver transplantation, Living donation, Traveling and LTx, Vaccinations and LTx, Transplantation follow-up care, etc. We'll be happy to inform you.**

 **Lebertransplantierte  
Deutschland e.V.**

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**Waiting for a LTx**

## Information for Patients Waiting for a Liver Transplantation



 **Lebertransplantierte  
Deutschland e.V.**

8. Auflage · Juni 2010

## Waiting for a liver transplantation

Chronic liver diseases often lead to cirrhosis of the liver. At the very latest, when the liver function decreases and complications increase, the possibility of a curative liver transplantation comes up. The doctor treating you should refer you to a transplant center where it can determine if such an operation is advisable.

## Which TX-center should I choose?

You have the right to be referred to any liver transplantation center in Germany. It's best to discuss this ahead of time with your health insurance company to determine if they are willing to cover all your before and after costs, especially if you want to choose a center in another state from you reside.

There are no age limit restrictions for a liver transplantation. It depends much more on whether your body has the necessary strength to carry you through the rigors of such a major operation and the healing process afterwards.

If, in the opinion of one transplantation center, a liver transplantation is not an option for you, then it is still okay and sensible to get the opinion from a second liver transplantation center.

## How do I get on the waiting list?

After checking in to a transplantation center, the doctors will determine – on the basis of your medical records – if a transplantation might be helpful. If they find it promising, they will conduct an array of medical tests. They check the function of the liver, heart and lungs, bone density, different blood tests and even check your teeth. All of this is necessary to get an exact overview of your current condition. Only then do they have all the facts necessary that are important for the success of a transplantation.

When a liver transplantation is possible, the center will register you with Eurotransplant. This international group distributes donated organs to the transplantation centers. Your transplantation clinic must inform you if, when, and with which priority you have been placed on the waiting list. If there is any change in your status, e.g. a worsening of your condition, or if due to an acute illness a transplantation is momentarily impossible, the center must also notify you. Make sure you get the telephone number of your transplantation center, so that you and your doctor can contact them if you have any questions or problems.

## How long do I have to wait?

No one can really predict how long one will have to wait. This depends upon many different factors, including your blood type, the number of patients on the waiting list and the number of donated organs. On top of that, your physical fitness also counts. It affects your ranking on the national waiting list. Of course, patients that are critically ill can't wait as long. The measure used as a rule to measure one's urgency is the so-called "MELD" (**M**odel of **E**nd-Stage **L**iver **D**isease) score. An overview of this method is given in the table at right.

## What responsibilities does my doctor have?

Always inform your doctor what was discussed with the transplantation center, and request them to maintain close contact with the transplantation doctors. Visit your doctor often during the waiting period for regular check-ups.

If your condition worsens, you should immediately notify your doctor. Then he/she can quickly notify the transplantation clinic, especially if this might move you up on the waiting list. Also request your doctor, after consulting with the clinic, to bring all your vaccinations up to date as necessary. After the transplantation, some

vaccinations may either no longer be given or are no longer effective. The Standing Vaccination Commission of the Robert-Koch-Institute especially recommends vaccinations against Hepatitis A and B, as well as annual flu shots for all patients with liver diseases.

## Guidelines for Organ Procurement

### 1. Blood type

for both donor and recipient

### 2. Urgency/MELD score

Distribution is according to need: whoever faces the greatest risk of dying comes first. At the very top are "high urgency" patients with acute liver failure, or organ rejection within 14 days following a transplant. Then distribution is according to the MELD score, a number determined by blood tests to determine the serum bilirubin, serum creatinine and the INR (international normalized ratio for prothrombin, or blood clotting). The higher the MELD score, the more urgent the transplantation. With some diseases, the MELD score cannot be applied, as they require special rules.

### 3. Preservation time

This is affected by the transit time from the donor to the recipient. The shorter the better.

### 4. Waiting time

If the urgency of two patients is the same judging by the first criteria, then the second criteria decides, etc. How quickly one receives a liver depends above all on how many suitable organs are donated.

*(as of Dec. 15, 2007)*