

LIVER TRANSPLANTATION

A Handbook for Patients, Their Relatives and Loved Ones

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Introduction

As you read this Handbook, you may be encountering liver transplantation for the first time. You may well be experiencing feelings of anxiety if your doctor has told you that you can no longer live with your old liver and that you will need a new one for your future life. But the best treatment for liver failure patients known today is liver transplantation. Every day throughout the world, liver transplantation offers the chance of survival and to return to a healthy, active life to a great number of people. Success rates for liver transplantation have risen rapidly in recent years. Survival rates and the quality of life for post-transplant patients have also improved with the development of new medications and surgical techniques.

This Handbook will give you and your family information about liver transplantation from living donors and from deceased donors (also known as cadaveric donors). I hope you will be able to find the answers to some of the questions you have in mind. Changes you will need to make in your new lifestyle and all factors that you need to consider are all explained in [details](#).

We want you to be fully informed about your new liver. This will help you to acclimatize and live in harmony with your new life and speed up the recovery and recuperation period.

I wish all of you, patients and loved ones alike, every happiness in your new lives.

Prof. Dr. Yaman Tokat

1.

THE LIVER

The liver is the largest organ in the body, situated in the upper right part of the abdomen, behind the lower ribs and below the lungs. The liver has a number of functions. Some of these are listed below:

- It converts the food you eat into nourishing substances that your body can use (for example, it turns starch into sugar, produces bile for fat digestion, etc.)
- It produces blood clotting factors, enzymes and other proteins
- It stores iron, vitamins and energy sources (for example fats and sugar)
- It cleans toxic substances that might harm your body such as medication and alcohol

Liver Disease

The liver has a remarkable capacity to regenerate itself and recover from various diseases. But in some cases the liver is damaged beyond repair. This might be caused by hereditary factors, excessive alcohol or chemical abuse, cancer or infectious viruses that give rise to hepatitis. We call the state when the liver hardens and shrinks, developing swellings of various sizes, cirrhosis. Cirrhosis of the liver can lead to bleeding, jaundice, abdominal water retention (acid), infections and the retention of toxic waste that can in turn cause fatal results such as coma. When matters reach that point, the only life-saving option is to replace the diseased liver with a healthy one by transplantation. In such cases, liver transplantation is simply the only way to save the life of the patient.

The most obvious indication of liver disease is jaundice (yellowing of the eyes and skin). Jaundice is caused by an excessive amount of bile products in the blood.

BEWARE!!!

- Dark colored urine
- Confusion or coma
- Vomiting blood
- The body becomes easily bruised and tends to bleed
- Grey or clay-colored faeces
- Abdominal water retention (acid)
- Extreme weakness
- A tendency to shiver while going to sleep

...are all indications of liver disease

Liver disease:

- Jaundice
- Abdominal water retention
- Bleeding
- Confusion – coma

2. LIVER TRANSPLANTATION

Once your doctor has confirmed that you or your child needs a liver transplant, there are two possible ways forward:

- ✓ Deceased Donor Liver Transplantation → Deceased Donor Liver Transplantation
- ✓ Living Donor Liver Transplantation

A. Deceased Donor Liver Transplantation

This kind of transplantation can be carried out upon the granting of authority by the family of someone who has suffered brain death as the result of a traffic accident, brain hemorrhage, brain tumor or heart attack, that their organs may be donated to another person. Checks are made to ensure that the donor organs are not carrying any infectious diseases, cancer or liver disease. The liver is then removed and stored in a special liquid: the organ must then be transplanted within a maximum of 24 hours. Unfortunately, in Turkey as in many other countries, few organs are donated in this way and the waiting lists are long.

If you are on the cadaveric organ waiting list, you should always be accessible by telephone (preferably your mobile telephone) 24 hours a day. You should also keep a list of those who will be donating blood for the operation.

B. Living Donor Liver Transplantation

This is a surgical method in which part of the healthy liver of a living donor is transplanted into the patient who required a new liver.

The voluntary donor needs to be the parent, sibling, spouse or any relative up to the 4th degree of consanguinity, according to Turkish Law. All tests carried out on the potential donor must establish that there is no objection to that person donating part of his or her liver. These tests are in two parts:

First – Examinations are made to establish that the potential donor is in a fit state to go through the operation. These tests focus on all the main organs of the body such as the heart, lungs and digestive system, and the potential donor's psychological condition.

Second – Examination of the liver. These tests involve taking what we might call a map of the liver with all its structural features, veins, arteries and bile ducts.

If all tests are affirmative, that person can become a donor. In general, the left lobe is transplanted into young children, the right lobe into adults or older patients.

Essential Information for Living Liver Donors

The chance to benefit a loved one, to save them from disease and return them to life is a wonderful feeling. And nothing can compare to the happiness of doing this by donating a part of one of your own organs.

Nonetheless, the idea of giving up part of your liver may initially cause anxiety. You may be concerned about how this might affect your future health.

You should not forget that your liver will begin to regenerate and regrown immediately after the operation and will return to its original size about 3 months after surgery. Likewise, the part of your liver that has been transplanted into the recipient will grow into a normal sized liver within 3 months.

After you have made the decision to become a donor, detailed tests and examinations are taken to prevent any harm to your health and wellbeing. In the event that these tests reveal the slightest suspicion that any harm may come to you, then you cannot be accepted as a donor and this will be fully explained to you and your loved one. In this case the next step is to try to find another voluntary donor.

Tests Carried Out on Potential Liver Donors

1. Complete blood count
2. Liver tests
3. Serological markers (Viral hepatitis, HIV, etc.)
4. Chest X-ray
5. ECG and echocardiography
6. Abdominal ultrasound
7. Computerized Tomography (CT)

8. Magnetic Resonance cholangiography (MRC)

To be a liver donor you should be between the ages of 18 and 60. Although there is no definitive rule about this, problems faced by the over-60's mean that it is difficult for them to become donors. The first condition that needs to be fulfilled is that the donor's blood group needs to be compatible with the recipient's. This is summarized in the table below

Blood Group	May be a Recipient From...	May be a Donor to...
O	O	O - A - B - AB
A	O - A	A - AB
B	O - B	B - AB
AB	O - A - B - AB	AB

- Rh factors have no relevance in liver transplantation
- In some exceptional circumstances, and in the case of babies, it may be possible for transplantation to be carried without blood group conformity.

Preparing to go to Hospital

It is a good idea to keep a bag packed at home ready to go. That way you will not waste any time when it is time to go to hospital. You should keep the following items in the bag:

- Pajamas / nightgown
- Slippers
- Underwear
- Sportswear, T-shirts and socks
- Sponge bag (shaving gear, toothbrush, etc.)
- Books

It is recommended that you have a dental check-up while waiting to go to hospital so that any pre-transplant management can be done. This will reduce the risk of post-transplant infection. If you are receiving part of a relative's liver, both donor and recipient should be admitted to the hospital a few days before the operation. The items listed above will be needed by both donor and recipient.

Preparing for the Operation

When you get to the hospital, certain tests will be carried out. These are routine pre-transplant procedures designed to establish that there is no indication of infection. You will have a general check-up, blood and urine tests, a chest X-ray and electrocardiogram. You will then be asked to clean your entire body with an antiseptic soap and the staff will shave the incision area.

The transplant surgeon and anesthesiologist will talk to you to explain the operation process and associated risks. You will be asked to sign a consent form.

From the moment the transplantation team calls you to the Hospital:

- **Do not eat or drink anything**
- **Inform your relatives**
- **Do not smoke**
- **Go to the Hospital without delay**
- **Stay calm!**

Operation Procedure

Cadaveric liver transplantation surgical techniques have a background of 25 to 30 years. In recent years great strides have been made in surgical techniques; success rates have improved while complications have significantly decreased. But it is still a challenging operation that takes an average of 6-12 hours.

The entire liver is removed from the patient and replaced with a healthy liver. However simple that sounds, the operation can cause heavy bleeding and generally requires a team of transplant surgeons, surgical assistants, nurses and anesthesiologist.

The patient's liver is dissected from four main blood vessels. The bile duct that connects the liver to the intestines must be detached from the intestines. The new liver is then put in place and the operation is completed with the reconnection of the bile duct with the main blood vessels.

Living donor liver transplantations began to be carried some years ago; the procedure has been significantly developed over the past decade or so. In this operation, the two teams who remove and replace the liver generally work in tandem. The part of the donor's liver that is removed is inserted in place of the patient's liver, taking care to protect the recipient's main abdominal vein (vena cava). From the perspective of surgical technique, this is a much more difficult operation than cadaveric transplantation, and it requires a larger team. In addition, microsurgeons are needed to stitch the miniscule artery, and specialist radiologists perform ultrasound examinations that are carried out throughout the operation. The operation to remove the liver from the living donor takes 6-8 hours, the recipient operation 8-12 hours.

Even during the operation, the procedure may have to be cancelled or postponed in the event that the donor organ turns out not to be compatible.

T-tube/ Biliary Catheter Attachment and Bile Drainage

Your surgeon may regard it as necessary to place a small tube (T-tube / biliary catheter) into the bile duct. The T-tube drains bile out of your body into a small pouch known as a bile bag. The quantity of bile, ranging from a dark golden color to dark green, can thus be measured. Once the T-tube has been

attached, it can remain connected to the bag for one or two weeks, or even for longer. If no bile leakage is observed in the cholangiography, generally taken on the tenth day, the T-tube/Biliary catheter is capped. It generally stays in place for 3-6 months, sometimes longer, for the benefit of the patient's recovery and to facilitate special tests.

The T-tube is attached to the skin by means of a stitch and the dressing around it may need changing if it becomes moist. The transplant nurse will show the patient how to change the dressing without pulling out the T-tube, otherwise this procedure will be done during hospital visits.

After the Operation

The patient is taken to the intensive care unit after surgery, and connected to a respirator. If everything goes well, the respirator is gradually withdrawn within 12-24 hours, although you may remain on the respirator for longer if necessary. Abdominal drains are designed to drain fluid from around the liver and are generally removed before you return home.

After a few days in the intensive care unit, you will most probably spend two or three weeks' recovery period in the transplantation unit before being allowed home. For some time you will be under observation for any signs of organ rejection such as high fever, pains, jaundice, fluid retention, medication side effects and elevated liver tests. In this post-transplant recovery period, you will undergo intensive physical and mental rehabilitation and the speed of your recovery will depend to some extent on your own efforts.

Liver Biopsies

If there is indication in order to monitor your recovery, our transplantation team may take small tissue samples from your new liver. This procedure is known as a biopsy and is generally carried out to check on organ rejection. Biopsies can be conducted as a day-procedure. Before the biopsy a local anesthetic is administered by injection to the right side of your abdomen. Then a small sample is taken from the liver tissue with the aid of a special needle (Hepafix). You should lie on your biopsy-side for a period of one hour after this procedure and remain in bed for about 4 hours.

Out-Patient check-ups after discharge from hospital

You will need to come to the transplantation unit for outpatient check-ups once or twice a week in the first month after your discharge from hospital. The purpose of these check-ups is to follow your recovery and identify any possible complications. Your liver functions will be thoroughly examined each time; in this way, any infection can be detected and addressed.

You will be asked for a blood sample in order to measure the levels of tacrolimus (Prograf) and cyclosporine (Neoral) in your bloodstream and determine your medication accordingly. Excessive medication dosage can lead to the risk of over - immunosuppression and higher infection risk. On the other hand, under-immunosuppression can cause organ rejection. As the risk of infection or rejection decrease in time, the frequency of polyclinic check-ups declines.

The aim of these follow-up visits is to follow your recovery and to identify any possible complications.

- **Do not take Prograf and Sandimmun immediately prior to blood tests – these will influence the results.**
- **Bring your medication list and this Handbook with you on every visit; you can thus take note of any important information.**

3. POST-HOSPITAL CARE

Up to now you have been under the close care of the transplantation unit's medical team, but now the time has come to leave hospital...

From now, much of the responsibility for your care will be in your hands. But don't forget that the transplantation team is always there to help you whenever you need them.

Care of the Surgical Wound

Keep the wound clean using an antiseptic soap. If you notice any redness, swelling or fluid around the wound, inform your doctor without delay.

T-tube/Biliary catheter Care

If you have a T-tube/biliary catheter for bile drainage, there is the possibility of infection at the point of entry on your skin.

What to Do:

- **Clean the area around the tube with antiseptic soap.**
- **Avoid any sudden movements that may cause the T-tube to become detached or damage the wound**

Following your temperature

If you feel feverish, shivery, discomfort or pain in any part of your body, you should take your temperature. It could be the first indication of infection or rejection. If your temperature remains at or above 38 degrees for more than a day, contact your doctor or the transplantation team immediately. Do not use any medication without your doctor's approval.

Do not use any medication without your doctor's approval.

Blood Pressure and Pulse

Your nurse will show you how to measure your blood pressure and pulse rate. It is important that you know your normal blood pressure and pulse rate so that if you notice any variation from your normal values, you can inform your doctor.

You should call your doctor or the transplantation team if you notice any of the below:

- Redness around the T-tube/biliary catheter on your skin
- Feeling of heat around the T-tube/biliary catheter area
- Any fluid in the area
- Detachment of the stitches connecting the T-tube
- Any visible change along the T-tube/biliary catheter

Dental Care

You should use a soft toothbrush in order to avoid damaging your gums. Brush your teeth after every meal and gargle with antiseptic mouthwash. If you wear dentures, clean them thoroughly after every meal.

It is important to go to your dentist every 6 months for a general check-up to prevent infections and cavities. You should not go to the dentist for a period of 6 months after your operation, unless there is a serious problem. However long after the transplantation operation, you should always make sure you take antibiotics starting 24 hours before any dental surgery until 48 hours afterwards. This kind of precautionary treatment is called “prophylaxy”; your doctor will tell you what antibiotics you should take.

It is important to go to the dentist regularly to avoid infections and cavities.

General Body Hygiene

To keep infection risks down, it is important that you maintain the highest standards of personal hygiene and cleanliness.

- Wash regularly, shower rather than bath
- Use liquid soap rather than a bar of soap when washing your hands
- Refresh your hand and face towels daily

- Wash your hands before eating and after using the toilet
- Keep your nails clean with a nailbrush and soap
- Women who are menstruating should change their pads and tampons regularly, and keep the area clean using mild soap and water.

Since they are the ideal place for blood bacteria to develop, women should regularly change their pads and tampons. Do not use any women's hygiene products as they contain disinfectants that increase the risk of infection by destroying microorganisms normally found in the vagina. Cleaning with mild soap and water is sufficient.

Skin and Hair Care

Cortisone can cause spots on your face, chest, shoulders and back. If you have any spots, wash the affected area with a mild antibacterial soap three times a day and make sure that you rinse off the soap thoroughly. Avoid itching the affected area and do not use any cosmetic products to cover the spots. **(Remember that generalized or infected spots should be treated by a dermatologist)**. If the problem continues severely, contact your doctor or our transplant team for advice.

If your skin is very dry, you may temporarily stop washing that area to allow your skin to regain its normal moisture. Use a mild soap and body cream after your shower. Cortisone will probably also affect your hair. Permanent hair dye, mild dye, gel and bleaching products can cause your hair to weaken and split; they should be used with care. Using a good hair moisturizer will strengthen your hair.

Unwanted Hair

One of the possible side effects of immunosuppressive medication, especially cyclosporin, is the growth and spread of facial hair. This can be distressing for women and children, but under no circumstances should you stop taking immunosuppressive medication. Use depilation cream or bleach the hairs. Waxing and electrolysis can also be effective in removing unwanted hair. If the problem becomes severe, contact your doctor for advice.

Exposure to the Sun

Excessive exposure to the sun is harmful to everyone. The sun's ultraviolet rays can cause premature ageing of the skin, sunburn and skin cancer. Transplantation patients have an increased risk of skin cancer because the damage caused by penetration of ultraviolet rays into the skin cannot be totally overcome. As a result, you should always follow the following basic rules in protecting yourself from the sun:

- Avoid exposure to the sun when it is at its strongest (from 10.00 to 15.00). Stay in the shade as much as possible.
- When you are in the sun and without sun cream protection, wear a hat, long sleeves and light trousers.

Use a good quality sun cream of at least SPF 15 during spring and summer. Use the cream on all exposed areas such as your face, neck and hands. Sun creams wash off in water. If you have been perspiring or swimming, make sure to reapply sun cream regularly.

Remember that sun rays can be damaging even on cloudy days. Ultraviolet rays can cause sunburn when reflected off water, sand, snow and concrete. Do not use a solarium. Keep an eye on moles and marks on your skin. If you notice any change of color in such a mark, or that it is taking an irregular shape at the edges, inform your doctor without delay. Transplantation patients carry a higher risk of moles becoming cancerous because their immune system is suppressed. Always protect your skin from the sun.

4. LIFE AFTER THE TRANSPLANTATION

Patients who have had an organ transplant often describe themselves as having been reborn, and they think of starting a brand new life. Many celebrate the anniversary of the operation as their “Transplant Birthday”. A much better life awaits you after successful transplantation.

Returning Home

Getting back home after the transplantation is generally a joyous and emotional event, but this can turn into feelings of anxiety and even depression in the first weeks. It is important for you to be aware of the fact that the recovery period is one that will last weeks. It will take you, your family and loved ones some time to get used to this **new period living** with a liver transplant is a long learning process for everyone. Most people get through this process better when they remain active and make resolute steps to deal with the long rehabilitation period.

Nearly all liver transplantation patients return to their former state of health and life at the end of the most sensitive three-month period. Most people living with a transplanted organ regain their normal way of life, in spite of the possible problems. They work, have families, bring up children and play a productive role in society.

Diet and Nutrition

You were ill for a long time before the transplantation and you probably lost quite a bit of weight. Therefore maintaining a regular, healthy and balanced diet is an important factor in the recovery period and will help you get back on your feet. Unfortunately one of the almost universal side effects of cortisone is that it increases appetite significantly. So excessive weight gain is the leading long-term problem for many transplantation patients and you may feel the need to follow a low-fat, low-sugar diet in order to lose weight and keep your blood sugar under control. You should consult a dietician in order to draw up a balanced diet regime and eating & drinking plan tailored to your needs.

Your diet should include:

- Fruits

- Vegetables
- Grains and bread
- Skimmed milk and dairy products or other sources of calcium
- Lean meat, fish, poultry and other sources of protein

Important Nourishment Points:

Weight yourself every day

- Avoid excessive snacking on biscuits, cake and the like
- When you feel hungry eat a little fruit or (low calorie) vegetables
- Try to drink about two liters of liquids every day. This is of benefit to your kidneys and helps your body expel waste products. Bottled water, herbal teas, skimmed pasteurized milk and fruit juices are good options.
- Always clean and peel fresh fruit
- Always peel vegetables that grow in the ground such as potatoes and boil them
- Cooking vegetables in a pressure cooker preserves their store of vitamin, as well as saving time and electricity
- Do not eat raw vegetables like lettuce
- Do not eat moldy cheeses or cheeses made from unpasteurized milk
- Always buy small quantities of milk, cheese, oil, yoghurt and such products; this will ensure you consume them fresh

You may feel the need to follow a low-fat, low-sugar diet in order to lose weight and keep your blood sugar under control.

Salt (Sodium)

Another side effect of cortisone is that it causes the body to store salt. This can lead to water retention and high blood pressure. You should cut down on your salt consumption:

- Use small quantities of salt while preparing food
- Try not to add salt to cooked food
- Avoid salty products such as potato chips (crisps) etc.

- Avoid preserved products (they are generally very high in salt)

Exercise

Physical activity is as good for your body as your spirits. Patients who take regular exercise generally have a better feeling of wellbeing and say that it gives them energy for work, leisure and personal relationships. Exercise burns off the weight you have gained, and helps you to keep your weight under control.

It is also important to take daily exercise to strengthen your muscles that have got weak during a long period of illness. You should follow a graduated exercise program that slowly increases your exercise rate, to benefit from the advantages of exercise without straining or injuring your body. The best form of exercise is walking. A good walk in the open air will help you sleep soundly and make your bowels function better. Climbing stairs is a good way to begin your exercise program, but avoid excessive strain and relax if you feel tired. You will soon notice that your strength is returning and can try other forms of exercise. Cycling, swimming and walking are good for keeping up your muscle strength and if all goes well you should be able to start heavier exercise like tennis and jogging within three months after your operation. Taking exercise also helps prevent the bone erosion (osteoclasia) that is a side effect of some medication. Don't forget to consult with your doctor and transplantation team before beginning any exercise program.

WARNING

You should stop your exercise program if you notice any of the following symptoms, and not restart until your doctor advises it is safe to do so:

- **Pain or pressure in your chest, neck or jaw**
- **Excessive fatigue that is not related to lack of sleep**
- **Unusual shortness of breath**
- **Headaches or dizziness during or after taking exercise**
- **Continuously high or irregular pulse during or after exercise that has only emerged after the transplantation**

Driving

It is forbidden to drive for a period of four weeks after the transplantation.

Alcohol

Alcohol is broken down in the liver and can damage **the liver**; you should avoid alcoholic drinks.

Smoking

It is essential that you give up smoking! Smoking is bad for you and others around you. If you feel you need help, speak to your doctor, who will introduce you to the team who can guide you.

Advice on Sex

You may restart sexual activity a few months after a successful transplantation, if you feel up to it. Most men regain their sexual drive and most women regain their menstrual balance a few months after the transplantation. But some medications can reduce sexual functions. If you encounter any problems in this regard, you may request help from your transplant team.

Kissing your partner presents no problems as long as neither has a cold or flu, herpes or similar infection. It is advised that both people wash themselves well in soap and water before and after sexual intercourse.

Some immunosuppressive medication limits the effect of birth control pills. The best form of contraception and preventing infection is to use condoms. Another option is a diaphragm. Women should be consulted by a gynaecologist concerning the best option for them.

Fertility

Fertility for both men and women may turn quickly after transplantation. Women should discuss their plans about having children with their gynaecologist and the transplant team.

You should wait for one or two years before becoming pregnant. It is important that before becoming pregnant your liver is functioning properly, that there is no disease that might threaten either yourself or your baby, and you will need to follow a course of low dosage immune suppression treatment.

Vacation

There is no barrier to you having a holiday in your home country, or traveling abroad on holiday. Use your common sense and avoid places where there might be any health risk, exposure to untreated water or contaminated food. Discuss your holiday plans with your doctor before hand. Don't forget to take a sufficient store of medication to last you through your holiday and leave an address where you can be contacted.

Vaccinations

You should not have any live or attenuated vaccination such as oral polio or measles vaccination for children. You may have inactive vaccinations like tetanus but you must consult with your doctor or the transplantation team before having any vaccination.

Pets and Plants

It is not advised to have pets as they increase the risk of infection. On the other hand, having a pet is an important source of comfort in speeding up the recovery period for many patients. Fish, reptiles and small rodents carry the least risk of infection. Dogs are another option, short-haired breeds being easier

to keep. Because of the risk of toxoplasmosis, cats should be avoided. Birds, which carry the staphylococci bacteria, are also not advised.

If you have a pet, you should avoid any contact with its faeces and always wear gloves when cleaning its cage. Best of all, ask someone else to do that for you. Do not let your pet lick your face or hands; if this happens by accident, wash the affected area thoroughly with soap and water without delay. Keep any pet toys like artificial bones etc. clean and keep them away from your personal possessions.

Pot plants and herbs are not advisable, because of the risk of infection from microbes in the soil. For the same reason you should avoid working in the garden or any agricultural work for the first year after your transplantation. After that, start gardening gradually but avoid planting, gathering soil and the like and always wear gloves.

Housework

You should always keep the bathroom and kitchen clean, especially the fridge. There is no need for special disinfectants. Normal domestic detergents and liquid soaps are sufficient. Follow your normal routine in keeping other rooms clean and change bedclothes once a week.

5. IMMUNOSUPPRESSIVE MEDICATION

Your new liver is a foreign body and your immune system gears up to fight this invader. Immunosuppressant medication weakens your immune system's response and avoids the rejection of the transplanted liver. But these medications also make your body more prone to infection. Therefore there is a need to strike a balance between preventing rejections on the one hand, and continuing sufficient defense against infection on the other.

However, the degree of immunosuppressive protection that is required for the transplanted liver declines after the first post-transplant months. Nonetheless, some medication is required for some years after transplantation. You should not stop or change the dosage of your medication, without consulting your doctor.

All immunosuppressive medication has some side effects. Doctors have established certain combinations of immunosuppressive medications designed to reduce side effects while providing an ideal immunosuppressive balance. As a result, you will probably be prescribed a mixture of a number of immunosuppressive medications.

Your immunsystem** attacks your transplanted liver like a foreign material.**

Immunosuppressive medications will have to be taken for the rest of your life after the transplantation.

Since each patient reacts differently to these medications, each patient is prescribed an immunosuppressive medication regime according to his or her needs and responses. You should not be concerned if other patients are prescribed different medication, or lower dosages.

You will find a general summary of different immunosuppressive medications below. This information is not comprehensive and you should see your doctor or the transplantation team if you encounter other problems. You should bear in mind that most patients do not experience all side effects and these effects diminish over time as the dosage decreases.

Some immunosuppressive medications are used for the rest of the patient's life while others are only used as treatment during the rejection period.

Immunosuppressive Medication

The main immunosuppressive drugs currently used after liver transplantation are the following:

- **Corticosteroids**
- **Calcineurin inhibitors (Cyclosporine and Tacrolimus)**
- **Antimetabolites (mycophenolate mofetil)**
- **Mtor inhibitors (Sirolimus, Everolimus)**

Corticosteroids can be used throughout a patient's life in order to prevent rejection, or for shorter term periods in higher dosages as rejection treatment. Corticosteroids are produced naturally in the glands above the kidneys and most are required for normal tissue function. The body produces corticosteroids on a 24-hour rhythm, with greater concentrations being produced in the early hours of the morning, declining throughout the day. That is why you must take your corticosteroid medications first thing in the morning, so as to catch your body's natural rhythm. Some patients take one dose in the morning, others two doses a day, one in the morning and one in the evening. Corticosteroids are generally used with ciclosporin and tacrolimus.

You must take your corticosteroid medication first thing in the morning.

Use of Corticosteroids

Your dosage of corticosteroids will be calculated according to your weight, medical condition and how long has passed since the transplantation. Take the tablets with meals. If you are taking one tablet a day, take it at breakfast time.

Short-Term Side Effects

Corticosteroids have the following short-term side effects:

- Greater susceptibility to infection, deterioration in the healing of wounds and injuries
- Suppression of fever and other indications of infection

Elevated Blood Sugar

Leads to psychological changes ranging from a sensation of happiness to a state of agitation and confusion.

Long-Term Side Effects

The long term side effects of corticosteroids tend to be related to the total treatment dosage that is required. Corticosteroids may have the following side effects, depending on dosage:

- Distortion of distribution of body fat (Fat concentrating on the neck, cheeks, humpback)
- Bone erosion and weakening, muscle wasting
- High blood pressure
- Thinning of the surface of the skin and susceptibility to bruising and chafing
- Diabetes
- Cataracts
- Acne or an increase in facial hair growth
- Increase in appetite and weight gain
- Gastrointestinal side effects, ulcers or indigestion

Although this list seems pretty frightening, it must be stressed that today's low dosage use of corticosteroids against rejection mean that these bad side effects are less common than they used to be. And corticosteroids have advantages over other immunosuppressive medications: they do not suppress bone marrow, can be used in combination with other medications, and have no direct toxic effect on the transplanted organ.

Precautions

If you are pregnant or breast-feeding, the benefits of this medication must be weighed against its potential harm to you, your fetus and baby. If you think you are pregnant, you should consult your doctor or transplantation team without delay.

Cyclosporin (Sandimmune / Neoral)

After steroids, siklosporin is the most important medication group in organ transplantation. Siklosporin has been on the immunosuppression protocol since the 1980's and caused a significant decrease in organ rejection rates. Siklosporin acts to obstruct the effects of T-cells, (a kind of leukocyte). Siklosporin are generally taken orally in combination with corticosteroids and other medications.

Siklosporin's most important distinguishing feature is that it is absorbed in the intestine after being taken orally, and its absorption into the bloodstream is easily affected. Today, Neoral preparation is used instead of Sandimmun, and this problem has to some extent been overcome. As Siklosporin is fat-soluble, its levels in the blood are easily affected when a poorly functioning liver excretes high levels of the serum bilirubin or when for enterohepatic circulation reasons there is a bile tube. The rate of clearance from the blood can also be affected by the age of the patient. Children's bodies expel siklosporin more rapidly than adults.

The preferred form of siklosporin is a preparation that is taken orally. The generally used dosage is 10-20 mg/kg. Siklosporin must be taken regularly every 12 hours. It is crucial to monitor Siklosporin's effects on blood levels. In high dosages, Siklosporin can cause serious damage to your kidneys, causing numbness and shaking in the hands. A low dosage can lead to organ rejection. The most appropriate measurement is the level of Siklosporin in the blood 2 hours after it has been taken. You should be sure that you have taken siklosporin at the correct time the previous evening, and then it should be measured exactly 2 hours after taking it in the morning. Care must be taken not to break this schedule, even by 5 minutes. Your dosage will be calculated according to your weight, blood levels, medical condition, the laboratory test results and the existence of any evident side effects. In the first month after the transplantation operation, the serum levels must be checked twice a week. This follow-up measure gets less and less frequent as time goes by; after six months, it can be carried out once a month.

Siklosporin's most significant side effect is its effect on the kidneys. This effect varies according to serum levels. High siklosporin dosage can lead to kidney failure. The kidney can return to normal upon lowering the dosage. Siklosporin can also show toxic effects on the liver. Liver enzyme levels can become elevated in patients who are taking high dosages of siklosporin. Siklosporin can also have neurological side effects such as shaking hands, numbness, muscle weakness, elevated sensitivity to changes in temperature and epilepsy. To avoid excessive siklosporin dosages, the most appropriate method is generally to administer lower dosages in combination with other medication.

Cyclosporin non-kidney related side effects:

- High blood pressure
- Thickening of the gums
- Elevated blood fat levels
- Increased in hair growth
- Tremors

- Gastrointestinal problems such as diarrhea, nausea and vomiting
- Liver dysfunction
- Headaches

Most of these side effects can be mitigated or eradicated by lowering the siklosporin dosage levels. You should remember that you will probably not experience all these side effects, or even most of them, and that they will lessen in severity as the dosage declines. Siklosporin is affected by various commonly taken medications – you should consult with your doctor or the transplantation team before starting any other medication.

Tacrolimus(Prograf)

Like siklosporin, tacrolimus blocks T-cell function and obstructs their ability to attack and damage your liver. Although tacrolimus's structure is different, it has similar pharmacological effects as siklosporin. Tacrolimus is 10-200 times more potent than siklosporin. When used in the long term, there is not much difference between tacrolimus and siklosporin. But tacrolimus has been shown to be effective in reversing acute cases of organ rejection.

Like siklosporin, tacrolimus is used by measuring blood serum levels. This helps to prevent side effects and achieve the appropriate serum levels. Tacrolimus is taken twice a day at 12 hour intervals. Tacrolimus is available in 1mg and 5mg tablet forms. Blood levels must be measured 12 hours following the previous dose has been taken – in other words, just before taking the next tablet. If the patient is taking tacrolimus at 8 in the morning and then at 8 in the evening, the blood levels should be measured just before the morning dose is taken. Remember to bring your medication with you so that you can take your next dose of tacrolimus immediately afterwards. Your dosage will be calculated according to your weight, blood levels, medical condition, the laboratory test results and the existence of any evident side effects.

Tacrolimus and siklosporin have the same side effects. Tacrolimus can cause susceptibility to diabetes to a somewhat higher degree than siklosporin. Side effects from one may be observed when transitioning to the other. The possible side effects of tacrolimus are as follows:

- High blood pressure
- Slightly elevated blood sugar levels
- Sleep disturbance
- Numbness and tingling in the feet and hands
- Tremors
- Liver dysfunction
- Headaches

Most of these side effects can be mitigated or eradicated by lowering siklosporin dosage levels. You should remember that you will probably not experience all these side effects, or even most of them, and that they will lessen in severity as the dosage declines.

The tacrolimus team may change your medication from tacrolimus to siklosporin or from siklosporin to tacrolimus. This is done to prevent organ rejection and limit the side effects. Siklosporin and tacrolimus cannot be taken at the same time.

Tacrolimus is affected by various commonly taken medications – you should consult with your doctor or the transplantation team before starting any other medication, including non-prescription medications available from pharmacies.

mycophenolate mofetil (CELLCEPT)

Mychophenolate is an antiproliferative agent that has been used in clinics since 1995. Mychophenolate inhibits the enzyme in DNA purine synthesis and prevents the proliferation of lymphocytes responsible for the body's immune system. It is effective in suppressing the development of lymphocytes that activate the immune system. It is more effective, and has much fewer and less severe side effects, than the previously used azathioprine. It can have highly positive effects when used in conjunction with siklosporin and corticosteroids. Therefore it has made great contributions in lowering organ rejection rates. It obstructs rejection, in particular by suppressing the immune system's reaction. The most significant side effect of Cellcept are gastrointestinal complaints such as nausea, vomiting, diarrhea and peptic ulcers. It can also be associated with thrombosis and thrombophlebitis. Cellcept serum levels remain remarkably constant, and this agent is therefore used without measuring serum levels. Adults take a 1000mg dosage every morning and evening. Cellcept has a potent immunosuppressive effect and can therefore lead to infections. For this reason, patients are advised to monitor closely for any signs of infection after their transplantation operation.

Sirolimus (Rapamune) and Everolimus (Certican)

Rapamune is used by transplantation recipients in order to prevent organ rejection. This is achieved by suppressing certain cells in the body's immune system. Rapamune can be administered alone, or in conjunction with Prograf (tacrolimus) and Neoral (siklosporin).

Rapamune is available in 1mg. tablet form (as 30 or 100 tablet packages) or as a 60ml liquid oral solution in 1mg/ml concentration.

Rapamune is taken once a day orally and for maximum effect should be taken at the same time every day. Tablets are swallowed without chewing. The oral liquid solution is diluted with at least 60ml of water or orange juice.

Rapamune's side effects vary depending on blood levels. The most common side effects are:

- Increased risk of infection

- Nausea
- Diarrhea
- Anemia
- High cholesterol and triglyceride levels
- Headaches
- Acne
- Arthritis
- Muscle cramps

These side effects are generally reduced when the dosage is reduced.

While using Rapamune, you must not deviate from the dosage and frequency advised by your organ transplantation nurse. You can check your dosage and times by calling the organ transplantation center at any time. Due to Rapamune's pharmacokinetic effects, if you are taking Rapamune together with Prograf or Neoral, you should take these medications at least 4 hours before or after taking Rapamune.

Rapamune can be administered immediately the organ transplantation operation, or some weeks afterwards. The dosage for liver transplantation recipients is usually 2mg, but the actual dose for each patient is personalized according to their exact needs.

Rapamune is not administered to children under the age of 13. There is no need for dosage regulation in elderly patients or those suffering from kidney failure. The dosage of Rapamune may be increased during a rejection episode, or reduced in the event of infection or side effects.

If you forget to take your Rapamune, do so as soon as you remember. If the time when you remember is close to the time of the next dose, skip one dose and continue as normal. You should call the organ transplantation center if you forget to take your medication.

Rapamune's blood level is constantly monitored in liver transplantation recipients. As Rapamune follows the same metabolic route as Neoral, medications that effect Neoral levels also affect those of Rapamune. And since Neoral reaches higher blood levels by obstructing the metabolism of Rapamune, cutting or reducing Neoral dosages will also affect Rapamune levels. When dosages are changed, blood levels stabilize within 5-7 days and remain stable after that. For that reason, blood level checks are carried out once a week.

Rapamune tablets are taken at room **temperature**; **the** oral solution should be kept in the fridge. The oral solution can cause mouth sores. These sores disappear when the dosage is reduced.

Women who are thinking of conceiving should first consult with the organ transplantation doctor concerning Rapamune usage.

6. MEDICATION CHECKLIST

These rules apply to all medications:

- Take your medication at the same time every day
- Even if you feel better, you should never change or cut your dosage
- If you take more than your **dosage by mistake, you** should inform your doctor without delay
- Remember that your medication is only for your use
- Never use any medication that has gone beyond its sell-by date
- Return any unused medication to the transplantation center
- Inform your doctor or the transplantation team if you experience any new or unusual side effects
- Do not take any non-prescription medication without your doctor's approval
- Keep medication in a cool, dry, dark place beyond the reach of children
- Do not keep your medication in the fridge unless expressly advised to do so by your doctor or pharmacy
- Make sure you have a sufficient stock of medication for weekends, or before you go on a trip or long holiday

7. POST-OPERATIVE COMPLICATIONS

It is not so unusual for any patient who has had a serious operation to experience certain complications. In most transplantation patients with complications, they arise in the first few weeks after the operation. So you should not worry if you do encounter difficulties. Your transplantation team will do all they can to minimize the risk of complications, and rapidly address any that do arise.

Rejection

Many patients experience one or two rejection episodes in the first weeks after their transplantation operation. At first there may be no indication of rejection and you will generally feel well, though you may feel small changes such as slight fever or general weakness.

You should be conscious of the following indications of rejection:

- Tiredness, weakness
- Abdominal pain or sensitivity
- Dark yellow / orange colored urine
- Putty-colored feces
- Tests showing liver dysfunction

Rejection Treatment

If you think you are experiencing a rejection episode, this can generally be verified by means of a liver biopsy. If the rejection is of moderate or severe level, pulse steroid treatment will be carried out for three consecutive days. A biopsy will be carried out one week later to establish whether the treatment has succeeded or not. If the rejection continues or worsens after the steroid treatment, or if rejection reoccurs within a short period of time, more potent immunosuppressants such as OKT3 or ATG may be administered. A biopsy is carried out one week after OKT3 treatment to see whether it has worked or not. With the new and more potent immunosuppressive medication available today, there are almost no cases in which rejection cannot be prevented.

Infection

Your immune system has to be suppressed in order to prevent rejection. But this also weakens our body's ability to fight infection. In the initial post-operation period you will notice that you are more prone to colds and flu.

Preventing Infection

The world around us is full of microbes and while it is important to restrict our contact with potential causes of infection, we do not need to live in a "bubble". There are precautions and measures that you can take to reduce the risk of infection to you and your family without drastically restricting your lifestyle. These precautions include:

- Taking enough rest
- Keeping a healthy and balanced diet
- Taking regular exercise and maintaining an acceptable weight range
- Avoiding public spaces such as shopping malls, theaters and cinemas during flu outbreaks
- Reducing contact with people with colds or flu-like symptoms
- Thoroughly washing your hands before eating and after going to the toilet
- If you cut or scratch yourself, clean the area thoroughly and cover the wound with a plaster

- Wear gloves when gardening or doing any “dirty” work
- Do not smoke

Signs of Infection

Sometimes infection cannot be prevented. If you experience any of the symptoms listed below, you should inform your doctor or transplantation team without delay:

- A fever above 38 degrees that lasts for more than one day (especially if it is associated with a chill)
- Diarrhea, nausea, vomiting or unexplained headaches
- Tiredness, lack of appetite
- Shortness of breath, burning while passing urine, abdominal pain
- Any change in the color of your skin or the whites of your eyes, skin rashes, pain or difficulty while swallowing

Abnormal Kidney Function

Abnormal kidney function can be caused in some patients taking siklosporin (Sandimmun) or tacrolimus (Prograf). Kidney function can easily be monitored through measuring urea and creatine levels. The toxicity of siklosporin and tacrolimus medications can cause kidney dysfunction and abnormally elevated levels of these two waste products. These side effects are generally related to dosage and can be kept under control by reducing dosage levels. It can be difficult to notice kidney dysfunction but you should contact your doctor or transplantation team if you notice increased urine flow at night, fatigue, or a reduced amount of urine even though your liquid intake is normal.

Diabetes

Diabetes makes your blood sugar levels increase. In the long term, diabetes can cause kidney failure, blindness, circulation difficulties and the loss of feeling in the arms and legs. Some of the immunosuppressive medication that you are using can be a cause of diabetes. If you notice any the symptoms listed below, you should contact your doctor or transplantation team without delay:

- Increased thirst
- Increased frequency of urine flow
- Blurred vision
- Confusion

You can reduce your blood sugar levels by losing weight, keeping a strict diet and taking regular exercise. It may be necessary to take an oral anti-diabetic medication or insulin injections. If you do develop diabetes, special treatment will be available to you in order to overcome the problem.

High Blood Pressure

As people grow older, high blood pressure and heart disease have become more common. You must take your blood pressure while taking certain medication as one of their side effects is to increase your blood pressure. If high blood pressure is untreated, it can lead to heart problems and the build-up of fat in the arteries. Therefore you may have to take additional medication to control your blood pressure, as well as a diuretic to increase urine flow and help the body to expel unwanted liquid and avoid water retention.

Lifestyle changes can also help to keep your blood pressure under control. Try to keep away from stress, follow a low-salt diet, give up smoking and take regular exercise.

Cancer

All immunosuppressive medication slightly increases the risk of cancer, especially B-cell (a kind of white cell) lymphoma. All patients taking immunosuppressive medication carry a certain risk in this regard but it is low (less than 3%). Transplantation patients' skin cancer risk is higher, so you must take care to protect yourself against the sun.

Neurological Complications

Cyclosporin and Tacrolimus can cause **sleep disorders problems** such as insomnia or nightmares. You may feel nervous and experience sudden mood swings. Some patients experience difficulty in concentrating and remembering things. You may notice that your hands shake or you feel a tingling sensation in your hands and feet. These side effects generally emerge shortly after the operation and can be mitigated by reducing medication dosage levels.

Psychiatric Problems

It is not unusual for transplantation patients to become anxious and depressed after the initial excitement has worn off. Some patients, especially women and children, are disturbed by changes in their appearance. You may fear that your post-transplantation life will not be as it was before you became ill, and fear becoming disabled or that your life will change for the worse. This can be aggravated by family problems or tensions. It can be hard for your spouse or family to understand your special needs, and what you are feeling. Counseling services exist to help you and your family in your home life and finally in the period preparing to return to work or school. Please **contact your doctor** or transplantation team to get more information about these kinds of services. That way, problems can be prevented or overcome.

Quality of Life

Replacing the liver in one person with that from another person is not like changing the engine of a car. You have to make some changes in your life, take medication every day and visit the out-patient unit. Even so, most transplantation patients' quality of life after the transplantation operation is far higher than it was before. Many regard the transplantation as representing a new chance to live, a fresh start in life and the chance to rebuild their future.

Most transplantation patients believe the quality of their lives is very high.

Keeping in Touch with Your Transplantation Team

This is your main responsibility. The moment that your liver tissue has been connected to your body, the purpose of medical care is the same as it is for any healthy person – preventing disease and overcoming any problems that may arise. There must be good communication between you and your transplantation team and other doctors. Be assured that all the doctors who are caring for you are aware of the medication you are taking and what needs to be done to maintain your good health. Keep an accurate and updated record of your medical details: it is crucial that you record blood pressure, pulse, medications and changes in dosages, infections and treatments, and any new indications or side effects.

8. GLOSSARY of TERMS

A

Anemia: a reduced level of red blood cells

Anesthetist: the doctor who provides and oversees anesthetics during your operation

Antacid: a medication that reduces acid levels in your digestive system to prevent or treat ulcers

Antigen: molecule that recognizes the need for, and activates, the body's immune system

Antibody: a protein produced by the body to destroy foreign bodies such as bacteria

B

Bacteria: small organisms that pave the way for disease

Bilirubin: a reddish-yellow pigment that is a constituent of bile and gives it its color, it emerges with the breakdown of red blood cells.

C

Cholesterol: a kind of oil found in the human body. At elevated levels it can lead to heart and arterial disease.

Cortisone: a kind of immunosuppressive medication

Creatine: a substance found in body fluids, blood and urine. Elevated levels indicate kidney dysfunction

CMV (Cytomegalovirus): An infection-caused virus commonly seen in transplantation patients

D

Diabetes: a disease characterized by high blood sugar levels

Diuretic: a medication that increases urine flow

E

Electrocardiogram: a record of your heart's electrical activity

Electrolyte: products such as sodium, potassium and chlorine dissolved in water

Enzyme: a protein produced in the body that converts one substance into another

F

Fetus: human embryo in the womb

H

Hematocrit: measurement of red blood cells

Hepatic: concerning the liver

Hepatologist: a doctor specializing in the treatment of liver disease

Herpes: a family of viruses that infect humans. Herpes simplex causes sores to the mouth and genital area. Herpes zoster erupts along a nerve path, often accompanied by severe neuralgia

Hypertension: high blood pressure

G

Gallbladder: a sac connected to the liver that stores bile

I

Intravenous: medication or fluid given directly into the vein

Immune System: a system (including the thymus, bone marrow and lymphoid tissues) that protects the body from foreign substances and pathogenic organisms by producing the immune response

J

Jaundice: yellowing of the whites of the eyes and the skin caused by excessive levels of bile in the blood

L

Leucocyte: blood cells that fight infection; part of the immune system

Liver: a large, reddish-brown, glandular vertebrate organ located in the upper right portion of the abdominal cavity that secretes bile and is active in the formation of certain blood proteins and in the metabolism of carbohydrates, fats, and proteins

O

Oral: by means or way of the mouth

Organ Rejection: the reaction of the body's immune system in recognizing a transplanted organ as a foreign body, not accepting it and trying to destroy it

P

Prophylaxy: the preventative use of medication.

Potassium: a mineral required by the body

R

Renal: to do with the kidney

T

Thrombocytes: blood cells required for normal blood clotting

T-cells: Leucocytes that play a key role in organ rejection

T-tube: a tube that is surgically connected to the bile duct to drain bile from the body into a pouch

U

Ultrasound: The use of ultrasonic waves for diagnostic or therapeutic purposes, specifically to image an internal body structure, monitor a developing fetus, or generate localized deep heat to the tissues. It also plays a role in collecting fluids such as blood or bile. First a lubricating gel is rubbed onto your abdomen and then a metal instrument will be run **along the area to images that appear** on a screen

V

Ventilator: a machine that helps a patient to breathe

Virus: a very small agent (microbe) that causes infection