

Veien videre - lever

Oversettelse til engelsk

The Road Ahead: Liver (short version)

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Immunosuppressive medication

Immunosuppressive medication is vital for preserving your new organ. You must always take the medication as prescribed by your doctor. It is important that you know how the medication works and its side effects.

This increases the risk of rejection:

- If you stop taking the medication. This will cause you to lose the new organ.
- If the medication is not sufficiently absorbed in the gastrointestinal tract. This can happen if you vomit after taking the medicine, or with diarrhoea. If this lasts for more than a day, you must contact the doctor who is scheduled for your check-up to take the medicine intravenously.
- Failure to follow instructions concerning dosage, storage and when to take the medication can lead to rejection, or at best unnecessary side effects.
- Taking other drugs or natural remedies that affect the uptake and degradation of immunosuppressive medication.

Medication dosage

The medication and dosages you receive are specially tailored to you. If the dose is too high, you may get unnecessary side effects; if the dose is too low, your body

may reject the organ. This is a balancing act, and based on blood tests your doctor will decide how much medication you should take.

Date/time

It is your responsibility to take the medication at a fixed time to get the best possible effect, and to get the correct result from blood tests. You will receive information at the hospital about blood tests and when to take the medication.

Did you forget to take a dose of immunosuppressive medication?

What to do if you forgot to take your medications depend on which medication you are taking and how long you forgot to take them.

If you forgot

Prograf/Sandimmun/CellCept/Myfortic/Certican:

0-4 hours after morning dose, take regular morning dose immediately.

4-8 hours after morning dose, take half morning dose immediately and regular evening dose.

8-12 hours after morning dose, take one and a half (1.5) usual dose at once, and do not take the evening dose.

If you forgot the evening dose, the same principle is followed.



When you forget to take Advagraf:

0-18 hours, take the usual dose.

18-24 hours, take the usual dose and wait with the next dose until 12 hours have passed, then take the next dose at the usual time in the morning.

When you forget Prednisolon:

Take the missed dose as soon as you remember and continue as usual.

Have you missed two doses or are unsure of what to do?

Call your control point for advice!

If you vomit after taking your immunosuppressive medication within 30 minutes, take a new dose. If you vomit again, or if nausea/vomiting creates problems *with two consecutive doses*; contact the department you are being monitored at.

Never change your medicine dose yourself!

Rejection

Most rejections occur from one to three weeks after the transplantation. After two or three weeks, the risk of rejection diminishes, and after three months rejection is relatively rare.

25-30 % of liver transplants are rejected. That means rejection is a natural part of the transplantation process. Most often, a treatment regimen will have a good effect on acute rejection.

Signs of rejection

With today's immunosuppressive medications, you will rarely discover a rejection yourself. The most important

thing you can do is take your medication and take it at the right time.

However, it is important that you are aware of any symptoms of transplanted organs not working properly.

The medications you receive reduce the body's own defences against infections. Therefore, always contact the place you go for a check-up if you develop a fever above 38 °C, or if you suspect infection or other illness. The emergency room may have little experience with transplant recipients, so they should only be contacted for emergency assistance or if you live far away from the office that carries out your control checks.


If you experience one or more of these symptoms, call the office in charge of your check-ups the same day:

- Fever, 38 °C or more.
- General malaise, which feels like flu symptoms.
- Darker urine.
- Lighter coloured faeces, or diarrhea.
- The whites of your eyes and skin become yellowish.

Make sure that your relatives and any travel companions know that you need medication every day, so they can get you admitted to a hospital in an emergency.

Generalities

- You should live your daily life as normal.
- Follow good rules for hygiene. Hand washing and oral care are particularly important.
- Protect yourself from the sun.
- In case of changes in your skin, tell the doctor who is monitoring you.
- You should give up smoking.

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- Do not drink alcohol at the beginning (for about 6 months). You can begin to drink moderate amounts of alcohol after that. If you were diagnosed with Alcoholic Liver Disease or Hepatitis C, you must abstain from drinking alcohol the rest of your life.
 - When contacting healthcare professionals, always tell them about the transplant and your immunosuppressive medication.
 - Other medications may alter the effect of the immunosuppressants, which may lead to rejection.

Contact the doctor who is monitoring you immediately if:

- A wound becomes red, warm, tender or if there is pus.
- If it takes a long time before the wound heals.
- If you have been exposed to chickenpox you should contact your doctor immediately. Getting a chickenpox virus infection can be very serious and treatment must be considered.

Oral care

Immunosuppressive medications can cause problems such as dry mouth, sores and infections in the oral cavity. This can be prevented by good oral and dental care.

We recommend that you brush your teeth and mouth three to four times a day until you are eating and drinking normally and are in normal activity. If you have dentures, you must remove them every time, clean the denture and brush your teeth and mouth. When you reduce your immunosuppressant doses, and you do not have special problems in the oral cavity, keep brushing morning and night.

Travel


If you plan to travel, you must plan well in advance! It is a good idea to make a checklist when you start preparing for your trip. In addition to usual documents such as valid passports, tickets etc., the list should include the following:

- Two sets of medication. Some feel safer bringing even a little extra.
- Travel pharmacy.
- Letter from your doctor.
- Prescriptions.
- Maybe a pharmacy certificate. Read the chapter "Hvor går reisen?".
- Travel insurance – It is important to find out what travel insurance covers in your situation and you must check with your own insurance company about what applies before you travel.
- European Health Insurance Card. This can be ordered online: www.helsenorge.no
- Address and telephone number of the Norwegian embassy or consulate in the country you are travelling to.
- Telephone number (contact information) of the doctor who is monitoring you.
- Plan what to do if something happens – It's important!

We recommend waiting at least 6 months after the transplant before travelling abroad.

Family and loved ones

The patient spends time processing thoughts and reactions about their situation and has the opportunity to talk to the staff about any concerns. Family and relatives do not have such close contact with staff and may feel left out. This is especially true of relatives who cannot be at the hospital; they may feel lonely, anxious and powerless to help. It



can often help to express your thoughts and feelings.

Relatives can contact the nursing staff and doctors at any time. We can help with conversations, information and a referral to a social worker, priest or psychiatric nurse if needed.

Diet

After the transplant, it is important to have a healthy diet. Some may have lost a lot of weight before the transplant and need to put on weight afterwards, while others maintain normal weight.

Prednisolon can give a more intense feeling of hunger than before and it is therefore important to make sure you do not develop severe obesity and thus new health problems. As a general rule, four to five meals a day are recommended; breakfast, lunch and dinner with 1-2 smaller additional meals. Eating regularly helps to regulate appetite and prevent large fluctuations in blood sugar.

Sugar

- You should limit your intake of sugar and sweet foods.
- Daily intake of a lot of sugar increases the risk of obesity and diabetes.

Fat

Due to the increased risk of obesity and high cholesterol when using immunosuppressive medications, you should pay attention to the amount of fat and the type of fat you eat.

The plate model

Imagine dividing a plate into three equal parts. One part has vegetables. The second part you fill with potatoes, rice, pasta or bread. The last part you fill with

fish, meat, legumes or eggs, and possibly sauce.

You should be careful about food hygiene and know about food risks. More about this is found in the chapter on Diet.

Physical exercise

After the transplantation, the medications you take make physical activity very important. Physical activity means everything from housework and walks in your neighbourhood to purposeful hard training. What is important is that you find the activity and the activity level that fits your lifestyle.

If regular physical exercise does not suit you, you should know how you can increase exertion in your daily activities and leisure time.


Cohabitation and sexuality

Many have had a lack or decreased desire for sex before the transplant. Most often, the desire returns after the transplant, but it can vary when it comes.

Side effects of medications can lead to erection problems. If this becomes a problem, you can seek help from the doctor who is monitoring you.

Women of childbearing age who stop menstruating during the illness usually get their period back after the transplant. The possibility of getting pregnant increases, so contraception is important.

Remember that **Takrolimus (Prograf, Advagraf) can reduce the effect of steroidal hormones, i.e. all types of birth control pills and injections, which makes prevention a little more difficult.** The doctor you discuss contraception with



should know about your transplant and immunosuppressive medications. If you hope to get pregnant, you **must** discuss this with the doctor who is monitoring you. Do not use Cellcept or Rapamune if you want to get pregnant. The transition to other medicines must therefore be planned carefully. At least 1-2 years must have passed since the transplant, and an organ functionality assessment must be made.

Some transplantees need treatment for CMV (cytomegalovirus). Treatment can have a temporary influence on reproductive abilities and can harm the foetus. Women should therefore use prevention as long as their treatment continues. Men should use condoms during treatment, and 90 days after treatment ends.

Social Media

It is very understandable that you want to share the great news about your transplant. We ask that you show some caution and restrain about what you wish to share online. Your social media update can be recognised by relatives, friends or acquaintances of the deceased.

Source criticism

Today we have increasing access to large amounts of new health information from many different sources of information. We therefore ask you to be critical of the information you find about transplantation. If you find new information, you should discuss what you are reading with your doctor